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HIV-RELATED STIGMA IN VIETNAM: IMPLICATIONS FOR THE PREVENTION AND CONTROL OF HIV IN CONCENTRATED EPIDEMIC SETTINGS

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Cover photo depicting rice processing in Bavi District taken by Martin Paucar

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ABSTRACT

Background: Since the early days of the HIV epidemic, stigma has been recognized as strongly linked to HIV. In concentrated HIV epidemic settings such as Vietnam, stigma is also associated with key risk groups that are heavily affected by HIV, such as injecting drug users, commercial sex workers and men who have sex with men. The availability of HIV prevention and treatment measures has increased globally, but the prevention, testing and treatment for HIV has lagged, particularly in certain segments of the population.

Aim: The overall aim of this thesis is to analyze and explore how HIV-related stigma influences HIV prevention and care in a concentrated HIV epidemic setting.

Methods: Data for this study were collected from three locations in Northern Vietnam and are organized into four articles (I-IV). In article I, a structured questionnaire was used to identify factors associated with HIV-related stigma in a population-based sample of 1874 adult community members in the rural district of Bavi. The same study population was used for article II, where determinants of HIV testing were identified. In article III, qualitative interviews with women living with HIV in and around Hanoi explored how women cope with HIV-related stigma. In article IV, focus group discussions with persons living with HIV and their family members in Quang Ninh province were used to explore factors influencing adherence to antiretroviral therapy.

Findings: Women, persons with less education, and those who had not migrated out of the rural area were significantly more likely to express stigmatizing attitudes toward people living with HIV, and HIV-related stigma was associated with not feeling at-risk for HIV among rural Vietnamese adults (I). Testing rates for HIV were low (7.6%), generally, and persons with less money, those living in more rural settings, and those expressing more HIV-related stigma were significantly less likely to have tested for HIV (II). Prevention of mother-to-child transmission programs seemed not to have had a large uptake in the study population, with pregnant women no more likely to have tested for HIV than non-pregnant women (II). Stigma appeared to affect the extent to which persons living with HIV could enact HIV prevention measures or disclose their HIV status to others (III, IV). Women living with HIV attempted to stave off HIV-related stigma by enacting culturally-prescribed feminine virtues of protecting others and appearing innocent in their infection with HIV (III). Family was identified as an important source of adherence and social support and those women who had more support from family members appeared to cope more easily with the stigma of living with HIV (III, IV). Organizations for persons living with HIV helped members to obtain health care and to manage stigma (III). Stigma was identified as one of the main barriers to adherence to antiretroviral medication, causing people living with HIV to hide or delay taking their medication (IV).

Conclusions: Results suggest that stigma presents an obstacle to effective HIV prevention and treatment in the Vietnamese context. The provision of free, opt-out, high-quality HIV testing could help to normalize the process of HIV testing and make it more accessible within Vietnam, particularly in the antenatal setting. Family and peer support could help to encourage good adherence to antiretroviral treatment. Organizations for persons living with HIV can be used to increase access to health care, to reduce stigma in community and family settings, and to increase quality of life for persons living with HIV. Refined public health messaging that incorporates the cultural notion of protection of family and that de-links HIV from fear-based messages could be an effective way of reducing stigma and increasing effective HIV prevention and care in the Vietnamese context.

Keywords: stigma, HIV, Vietnam, Filabavi, HIV-related stigma

LIST OF PUBLICATIONS

- I Pharris A, Nguyen Phuong H, Tishelman C, Marrone G, Nguyen Thi Kim C, Brugha R, Thorson A.
Community patterns of stigma towards persons living with HIV: A population-based latent class analysis from rural Vietnam.
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- II Pharris A, Nguyen Thi Kim C, Tishelman C, Brugha R, Nguyen Phuong H, Thorson A (2011)
Expanding HIV testing efforts in concentrated epidemic settings: a population-based survey from rural Vietnam.
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- III Pharris A, Tishelman C, Dinh Thanh H, Nguyen Thi Kim C, Thorson A.
Infected Innocent: Coping with HIV-related stigma among women living with HIV in Northern Vietnam.
(Submitted).
- IV Vu Van T, Pharris A, Thorson A, Alfven T, Larsson M (2011).
“It is not that I forget, it’s just that I don’t want other people to know”: Barriers to and strategies for adherence to antiretroviral therapy among HIV patients in Northern Vietnam.
AIDS Care. 23(2): 139-145.

These articles will be referred to in the text by their Roman numerals (I-IV).

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LIST OF ABBREVIATIONS

05 center	Mandatory education center for commercial sex workers
06 center	Mandatory education center for injecting drug users
AIDS	Acquired immune deficiency syndrome
ANC	Antenatal care
aOR	Adjusted odds ratio
ART	Antiretroviral therapy
ARV	Antiretroviral
CHC	Commune Health Station
CSW	Commercial sex worker
DOT	Directly-observed therapy
DSEP	Department of Social Evils Prevention
DSS	Demographic Surveillance Site
FGD	Focus group discussion
Filabavi	Epidemiologic field laboratory (DSS) in Bavi District
GFATM	Global Fund for AIDS, TB, and Malaria
HIV	Human immunodeficiency virus
IDI	In-depth interview (also called “open interview”)
IDU	Injecting drug user
MOLISA	Ministry of Labor, Invalids, and Social Affairs
MSM	Men who have sex with men
OPC	Out-patient clinic
OR	Odds ratio
PEPFAR	US President’s Emergency Plan for AIDS Relief
PLHIV	Person living with HIV
PMTCT	Prevention of mother-to-child transmission for HIV
RCT	Randomized control trial
SD	Standard deviation
UNAIDS	United Nations Joint Program on HIV/AIDS
VAAC	Vietnam Administration for HIV/AIDS Prevention and Control
VCT	Voluntary counselling and testing for HIV
WHO	World Health Organization

PREFACE

I had planned to focus the studies in this thesis on inequities in access to HIV prevention and care in Vietnam. My training in nursing and background in public health have shaped the way that I view the world, leading my professional interests and energies to focus on the places where individuals, health, and societal structures intersect. Before beginning this research in Vietnam, I worked on an HIV quality-of-care research project in Uganda and Zambia, and clinically as a nurse in the United States. Surprisingly, the barriers that individuals faced in accessing HIV prevention and care in those diverse settings were quite similar, although the resources levels and the burden of HIV varied greatly. When deciding to look at the issue of inequities in access to HIV prevention and care in a new setting, Vietnam, I expected the main barriers to HIV prevention and care to be due to geography, transportation, migration, or possibly to healthcare user fees.

As a first study, we planned a household survey within the Filabavi demographic surveillance site in a rural area not far from Hanoi. Karolinska Institute had collaborated with the site for several years and it was a good structure in which to examine health inequities. After a few weeks of the data collection for that study, a research assistant and I were asked by one of the surveyors to meet with a family who wanted to introduce us to their daughter. She was HIV-positive and was working as a housemaid in Hanoi. The family had called for her to come back to her home village in order to meet us. When we arrived, the family gathered around the living room, offered us tea, and her father told us her story. We learned that the woman, who I'll call Thuy, had been tested for HIV during pregnancy and that her husband, also found to be positive, died several months later. Thuy was living with her parents-in-law and had not received any follow-up care or referral for treatment during the four years since she had tested positive. She had never met any other person, besides her late husband, with HIV. Thuy's father wondered whether she should be taking medicine for her illness and, if so, where she could obtain such medicine.

Later we spoke with Thuy alone and she described great worry for her reputation and that of her family if community members were to know that she was HIV-positive. She feared that she would lose her job if anyone were to find out. She worried about whether it was safe to play with or sleep near her daughter, who was HIV-negative. Eventually, we accompanied Thuy to an HIV clinic in Hanoi and introduced her to the doctor there. The doctor informed Thuy that she would need to start receiving treatment very soon, as her CD4 cell count was just under 200/mm³ and that treatment would be free. The clinic was not far away from where she worked and she could attend the clinic on Saturdays, her day off. The doctor even counselled her as to what she could say to the woman for whom she worked, as to why she had to go to the clinic every Saturday (she suggested that Thuy tell her a story about needing diabetes care). The possibility for Thuy to begin and continue HIV treatment seemed very promising.

Several months later, while in Bavi district, a Vietnamese colleague came across one of Thuy's parents and asked how she was doing. She learned that Thuy had died a few weeks earlier. After meeting us, Thuy had tried to begin HIV treatment, but had decided that it was too risky to attend

the clinic for fear that her employer would find out. She also feared that she would bring shame upon her family if her status were to be known. She became acutely ill quite suddenly and went to her parents-in-law's home in a nearby rural area where she died, never seeking care in a health facility.

I share Thuy's story because it illustrates the issue that became the focus of this thesis: that stigma around HIV is very strong in the Vietnamese setting (as it is in many other settings). HIV prevention and care appear to be shaped by heavy stigma in Vietnam, which, as I will explore in this thesis, appears to powerfully influence the way that people think about and enact HIV prevention and seek and comply with treatment for HIV.

BACKGROUND

HIV AS A GLOBAL HEALTH PROBLEM

The oft-cited number of persons infected with HIV globally (33 million, 2.6 million of these newly infected during 2009) (UNAIDS, 2010a) sometimes obscures the enormous impact that HIV has had on individuals as well as families, health systems, and societal structures during the last 30 years. While HIV has been reported in every country in the world, the burden of HIV infection, in terms of the prevalence of disease in the population, is not uniformly distributed.

Variations in HIV prevalence within and between countries are closely tied to the timing of the introduction of HIV in the area, combined with the prevalence and frequency of individual risk behaviors, such as the sharing of drug injecting equipment or concurrent sexual partnerships, including unprotected transactional sex. In many settings, HIV tends to concentrate in defined vulnerable groups that have a high prevalence of one or several of these risk behaviors; these often include injecting drug users (IDU), commercial sex workers, and men who have sex with men (MSM). In such a setting, the HIV epidemic is often described as “concentrated”, which describes the current epidemiology of HIV in most of Asia, the Middle East, Europe, and the Americas (De Cock & De Lay, 2008). Throughout the world, the spread of HIV from key risk groups to the general¹ population has been linked to the transmission of HIV to the sexual partners of key risk group members, including to clients of sex workers. Elsewhere, HIV transmission is not sustained by the behaviors of key risk groups, and is mostly spread due to unprotected sex within concurrent sexual partnerships (and mother-to-child transmission of HIV) in the general population. Such settings are characterized as “generalized” HIV epidemics and this describes the current epidemiology of HIV in many countries in Southern and parts of East Africa (De Cock & De Lay, 2008). It is important to note that just as there is non-uniform distribution of HIV prevalence across countries, there is wide variation at the sub-national level in most countries as well.

There is increasing awareness that there is no “one size fits all” approach to preventing or responding to HIV. Wilson and Halperin (2008) proposed that local HIV epidemiology should be analyzed and the public health response tailored to local epidemic characteristics. This tailored approach includes balancing HIV prevention and HIV treatment efforts in differing epidemic settings, with more focus on prevention in concentrated HIV epidemic settings and a strong focus on both prevention and treatment in generalized epidemic settings (Lazarus, Curth, Bridge, & Atun, 2010; Wilson & Halperin, 2008).

Responding to HIV: ART and treatment as prevention

Since HIV was first identified in the early 1980s, the public health response to HIV prevention and treatment has been highly dynamic, with significant advancements seen in HIV treatment with

¹ The term “general population” is not intended to indicate that members of key risk groups do not constitute part of the population

the onset of combination antiretroviral therapy (ART) in 1996 (Merson, O'Malley, Serwadda, & Apisuk, 2008). There have also been advancements in the field of HIV prevention, the most successful being 100% condom programs among sex workers, needle and syringe programs and opioid substitution treatment targeting injecting drug users, prevention of mother-to-child transmission with ART, and male circumcision (Hagan, Pouget, & Des Jarlais, 2011; Klausner et al., 2008; Palmateer et al., 2010; Van Den Berg, Smit, Van Brussel, Coutinho, & Prins, 2007; Weiss et al., 2008). Also, structural interventions, such as cash transfer programs, have had promising results in some settings, pointing to the deep underlying structural issues and poverty that fuel HIV transmission (World Bank, 2010).

Prior to 2002, treatment for HIV was almost not available in the poorest countries, many of which had the largest proportional burden of persons living with HIV. Non-governmental civil society organizations, many of them groups of persons living with HIV, began to raise awareness of access to HIV treatment as a global human rights issue (Boulle & Avafia, 2005; Medecins Sans Frontieres [MSF], 2011). In 2003, as global trade agreements made ART more affordable, the World Health Organization set a target, via the "3 x 5 initiative" of having 3 million persons living with HIV in low- and middle-income countries on ART by the year 2005. This target, combined with unprecedented levels of financial support through large global health initiatives such as the Global Fund for AIDS, TB, and Malaria, and the US President's Emergency Plan for AIDS Relief (PEPFAR), accelerated the scale-up of the provision of ART in many low- and middle-income countries. It is now estimated that, according to 2010 treatment guidelines, about one-third of the population in need of ART in low- and middle-income countries is receiving treatment (WHO, UNICEF, & UNAIDS, 2010).

The scale-up of ART has been considerable, whereas the scale-up and coverage of prevention interventions to high proportions of populations that are most at-risk for HIV has been disappointingly low in most settings. This has resulted in a situation in which, in 2008, for every 2 persons who started ART, an additional 5 persons became HIV infected (Merson et al., 2008). Instead of re-doubling efforts to rigorously evaluate and apply effective behavioural and structural HIV prevention intervention measures, more focus has been placed on biological and treatment prevention efforts, including vaccine and microbicide trials and, more recently, treatment as prevention for HIV. Recent promising evidence has supported the effectiveness of vaginal microbicides to prevent HIV (Abdool Karim et al., 2010). Several randomized controlled trials have demonstrated that a daily oral dose of ART can prevent HIV acquisition among uninfected individuals (Grant et al., 2010; Thigpen et al., 2011; University of Washington International Clinical Research Center, 2011). Another trial among discordant couples recently demonstrated that earlier treatment of HIV-infected persons both had a clinical benefit for the infected individual and resulted in a 96% reduction in transmission to the uninfected sexual partner (Cohen et al., 2011). Modelling evidence has indicated that early testing and early treatment of all individuals with HIV could effectively halt HIV transmission at the population level (Granich, Gilks, Dye, De Cock, & Williams, 2009).

Despite increased funds for the global scale-up of treatment for persons living with HIV and promising evidence for the prevention of HIV through treatment and microbicides, the success of these measures is entirely dependent on people acknowledging their risk, on the uptake of prevention interventions and early testing, and on high levels of adherence to treatment. Globally, 60% of people living with HIV are not aware of their HIV status (WHO et al., 2010). Many of

these only become aware of their HIV status when they are very ill, often too late for treatment to be effective. Even those who test earlier and who are aware of their HIV status sometimes do not seek care or are not adherent to ART, causing viral resistance, treatment failure, and higher risk of death (Falster et al., 2009; Kumarasamy et al., 2010; Lawn, Myer, Orrell, Bekker, & Wood, 2009; McNicholl, 2008).

HIV-RELATED STIGMA

Stigma is almost universally defined using the language of Erving Goffman (1963), a sociologist who first described health-related stigma as, “an attribute that is significantly discrediting” and which, in society’s eyes, reduces that social status of the person or group that is the object of the stigma (Goffman, 1963). Further conceptualizations of stigma, particularly from the discipline of social psychology, have also focused on individual-level processes, defining the process of stigmatization as a labelling of differences associated with negative attributes that leads to separation, status loss, and discrimination, all of which are highly dependent on the possession or lack of power (Link & Phelan, 2001).

Since stigma was first conceptualized, it has been closely linked to certain diseases, such as mental illness, leprosy, and tuberculosis (Goffman, 1963; Long, Johansson, Diwan, & Winkvist, 2001; Stevelink, van Brakel, & Augustine, 2011; West, Yanos, Smith, Roe, & Lysaker, 2011). Having these diseases or being closely associated with them has been, and in many places still is, considered socially discrediting. For the most part, the concept of whether a particular disease is stigmatized changes over time or varies by culture. However, for certain diseases, some aspects of stigma seem nearly universal across time and place, existing for many decades across a number of cultures. Certain aspects of the expression of stigma appear to be very widespread, such as social or physical isolation of the individual or family possessing the negative attribute, however other expressions of stigma appear to be culturally-determined and vary from place to place (Abdullah & Brown, 2011).

The notion of stigma has been applied to HIV since the beginning of the epidemic, and HIV almost immediately became a disease condition associated with negative social attributes. HIV-related stigma is defined by UNAIDS as “a process of devaluation of people either living with or associated with HIV and AIDS” (UNAIDS, 2003). HIV-related stigma is an umbrella term that captures different aspects of the process of devaluation. Stigma can be conceptualized as internalized when experienced by an individual, and enacted when referring to discrimination imposed from outside, although self-imposed discrimination has also been described (Mahajan et al., 2008). Anticipated stigma is commonly described both in relation to HIV and to other diseases as being based on past experiences or fears of enacted stigma (Alonzo & Reynolds, 1995; Gilbert & Walker, 2010). Like other disease-related stigma, HIV-related stigma is created and expressed through a process of stereotyping (the devaluating “notion”), prejudice (the devaluating “emotion”), and discrimination (the devaluating “action”) (Phelan, Link, & Dovidio, 2008). The effect of stigma is highly dependent on social status and power (Castro & Farmer, 2005; Parker & Aggleton, 2003; Phelan et al., 2008).

Stigma² has been documented to lead to human suffering as well as many other negative effects on persons living with HIV (PLHIV) and their families, including depression, reduced quality of life, and lower adherence to medical treatment (Clum, Chung, & Ellen, 2009; Ogden & Nyblade, 2005; Sayles, Wong, Kinsler, Martins, & Cunningham, 2009). In addition to negative outcomes for PLHIV, HIV-related stigma appears to be associated with several potentially negative health behaviors for those who are not living with HIV. There appears to be a negative relationship between risk perception and stigmatizing beliefs towards PLHIV as well as HIV testing and stigmatizing beliefs in several settings (Bwambale, Ssali, Byaruhanga, Kalyango, & Karamagi, 2008; Campbell, Nair, Maimane, & Nicholson, 2007; Genberg et al., 2009; Kalichman & Simbayi, 2003; Liu et al., 2005; Pulerwitz, Michaelis, Lippman, Chinaglia, & Diaz, 2008; Riley & Baah-Odom, 2010; Smith & Morrison, 2006).

It is thought that HIV-related stigma affects men and women differently; however, the mechanism is not well-documented or well-understood (Ogden & Nyblade, 2005; Paxton et al., 2005; Sandelowski, Lambe, & Barroso, 2004; Shamos, Hartwig, & Zindela, 2009; Zhou, 2008). In some settings women are more likely than men to be sent away from their families when they are found to be HIV-positive (Bond, Chase, & Aggleton, 2002; Hong, Nguyen, & Ogden, 2004).

HIV-related stigma is often recognized as layered, with the degree of HIV-related discrimination and blame dependent on the manner in which the individual became infected with HIV. Because persons at the greatest risk of HIV, particularly in concentrated epidemic settings, tend to be members of socially devalued groups, such as IDU, sex workers, or men who have sex with men, there is significant stigma associated with risk group membership. An additional “layer” of stigma is added due to the individual’s HIV-positive status (Herek & Capitano, 1999; Y. Hong et al., 2008; Mahajan et al., 2008). The stigma associations derived from each of these negatively viewed attributes are often hard to disentangle (Chan & Reidpath, 2007; Chan, Yang, Zhang, & Reidpath, 2007).

In recognition of the close connection between HIV infection, stigma, and socially vulnerable groups such as IDU, sex workers, men who have sex with men, migrants, and in some contexts, women, HIV-related stigma is increasingly recognized as a societal structural process that mirrors and reproduces relationships of power and control, helping already dominant groups to legitimize and extend inequalities in society over stigmatized groups (Castro & Farmer, 2005; Parker & Aggleton, 2003). This has served as a critique of depicting HIV as an individual-level process or as something that resides in the person or group that is the object of the stigma. At the same time, while stigma is situated in a larger structural context at the societal level, it is also created and experienced at the individual and family levels and, therefore, can be measured and recognized at all three levels.

VIETNAM

The Socialist Republic of Vietnam lies in Southeast Asia and shares a border with China to the north, Laos to the West, and Cambodia to the Southwest. The official language is Vietnamese,

² While the general term stigma can refer to many diseases and conditions, it will be used, unless otherwise specified, to refer to HIV-related stigma for the remainder of this thesis. Some of the attributes of HIV-related stigma of course apply to other diseases and other forms of stigma, but a thorough examination of these is out of the scope of the focus of this thesis.

although additional languages are spoken by the more than 54 ethnic groups who live in Vietnam. The majority Kinh ethnic group comprises 86% of the total population (General Statistics Office of Vietnam, 2011).

Vietnam's recent history has been characterized by very fast economic growth and rapid social change. The poverty rate has decreased greatly, dropping from 37.4% in 1998 to 14.5% in 2008. Poverty has decreased the most in urban areas, where the poverty rate is 3.3% (General Statistics Office Vietnam, 2010).

Health status and health system

For its level of income and level of health spending, Vietnam's health statistics are above average. For example, Vietnam's infant mortality rate in 2009, which was 20/1000 live births (see Table 1), was similar to countries with much higher total gross domestic product and total health spending, such as Argentina and Ukraine (Gapminder Foundation, 2011).

Much of Vietnam's success has been attributed to its extensive public sector health care system, where health stations located in each commune provide a primary care access point and preventative care for populations of 3,000-10,000 persons. At the communal level, basic health care needs, including primary care, family planning, immunization, and prenatal care are provided. There is an extensive network of village health workers, trained by staff at commune health stations on topics such as immunization, sanitation, and basic health promotion. There are also polyclinics located in each district, where both preventative and curative services are provided. Each province has a hospital that provides more specialized care; these typically have 200 to 1000 beds, depending on the provincial population size. Finally, central level hospitals are available, mostly in the larger cities, and these provide highly-targeted specialist care for complicated cases. Although the public system is subsidized, there are user fees for services and "under-the-table" fees are common (Dao, Waters, & Le, 2008).

In addition to the system of public care, there is widespread use of private health care services, often due to fears about low quality of care in the public sector. There is an extensive and growing network of private providers. This has particularly increased since the "Doi Moi" reform policy in 1986, which ushered in a market-based economy and increased contact with ideas and products from outside of Vietnam as well as migration between rural and urban areas for work (Ekman, Liem, Duc, & Axelson, 2008; Phinney, 2009).

About 42% of Vietnam's population has health insurance coverage; however, it is estimated that about 70% of total health spending is out-of-pocket due to user fees and the purchase of medications and services that are not covered by insurance (Tran et al., 2010). There are some policies in Vietnam that provide health insurance cards and health care funds for the poor, but these are limited in scope.

Table 1: Basic population indicators for Vietnam

	Vietnam	Source
Population, millions (2009)	86	(GSO Vietnam, 2011)
Rural population, percentage (2009)	70.4	"
GDP per capita, PPP US\$ (2009)	3097	(UNDP, 2011)
Total expenditure on health per capita, PPP US\$ (2009)	213	(WHO, 2009)
Government expenditure on health per capita, PPP US \$ (2009)	82	"
Average life expectancy at birth, years (2009)		
Female	77	(World Bank, 2011)
Male	73	
Infant mortality rate, deaths per 1000 live births (2009)	20	"
Literacy rate, % adults (2009)	93	"
Fertility Rate, total births/woman (2008)	2.0	"
ANC attendance, percentage of women attending ANC ≥ 1 time (2006)	91	"

GDP= gross domestic product; PPP=purchasing power parity; ANC= antenatal care

HIV in Vietnam

In Vietnam, like many countries in Asia, the HIV/AIDS epidemic is still at a concentrated stage with an estimated HIV prevalence of about 0.44% in the general adult (15-49 years) population, corresponding to 254,000 adults living with HIV/AIDS in 2010 (Ministry of Health Vietnam, 2009). Although HIV prevalence is still low relative to some neighbouring countries, particularly Thailand and Cambodia, HIV/AIDS is now the third leading cause of mortality among male adults (Ministry of Health Vietnam, 2004; Ngo, Rao, Hoa, Adair, & Chuc, 2010; UNAIDS, 2010a).

HIV has spread to all 64 provinces in Vietnam and some provinces report prevalence rates of more than 1%. Sub-populations with higher prevalence rates of HIV are concentrated in the urban areas, especially in urban centers such as Ho Chi Minh City and Hanoi, as well as areas with large communities of IDU such as the mining districts in the northeastern part of the country. Based on the most recent bio-behavioral surveillance data from Vietnam, in 2009 HIV prevalence was estimated to be 18.4% among male IDU, 3.2% in female sex workers, and 16.7% among men who have sex with men (UNAIDS, 2010b).

In addition to high rates of HIV infection among the aforementioned risk groups, recent evidence shows the potential for acceleration of the epidemic due to low prevention behaviors among many members of key risk groups. There is evidence that condom use is low among CSW and MSM and that many IDU have shared equipment for injection drug use and have visited sex workers (National Institute of Hygiene and Epidemiology [NIHE], 2006; Nemoto et al., 2008; Vu, Girault, Do, Colby, & Tran, 2008). Not surprisingly, there is evidence that the epidemic is already beginning to spread to male clients of sex workers and to their female partners, as well as to sexual partners of IDU and MSM due to sexual mixing between these populations (Ministry of Health Vietnam, 2005; T. A. Nguyen et al., 2008). These new populations have led to an increase in infections detected among otherwise-seeming "low risk" women attending antenatal care who have been infected through their male partners' IDU or sex worker visits (Ministry of Health Vietnam, 2009).

In Vietnam as a whole, HIV testing is thought to be low, although it is not well-studied. Government estimates are that 35% of sex workers, 18% of male IDU, and 19% of MSM tested for HIV in 2009 and received their results. However, since estimates on total population numbers of those key populations are difficult to obtain, testing prevalence figures may not be highly accurate (UNAIDS, 2010b). It is estimated that only one-quarter of pregnant women are tested for HIV during antenatal care and, of those tested positive for HIV, the uptake of medication for the prevention of mother-to-child transmission is low, with only about one-third of HIV-positive pregnant women receiving ART (UNAIDS, 2010b).

The overall coverage of ART for those in need in Vietnam during 2010 was estimated to be 33% (based on WHO 2010 guidelines, 44% based on WHO 2006 guidelines), with a large unmet need for ART documented among certain sub-groups, including young women who are not connected to organizations for people living with HIV (Nam, Bygbjerg, Mogensen, & Rasch, 2011; UNAIDS, 2010b). Many persons present very late for HIV care in Vietnam; in one study in Ho Chi Minh City, 58% of men presented for HIV treatment with CD4 cell counts lower than 200 (Klotz et al., 2007; Nhac-Vu et al., 2010). This late presentation is linked to worse treatment outcomes and higher mortality (Falster et al., 2009; Kumarasamy et al., 2010). Although it is estimated that between 2 and 17% TB patients tested are co-infected with HIV, TB patients are often not tested for HIV in Vietnam, and the TB and HIV programs are not well-connected (Conseil, Mounier-Jack, & Coker, 2010; Thanh et al., 2010).

The Vietnamese policy environment

In 2007, Vietnam strengthened its legislation and extended protections for persons living with HIV, promoting their rights to HIV-related confidentiality, medical care, and to integration within the community, as well as prohibiting HIV-related stigma and discrimination (11th National Assembly of the Socialist Republic of Vietnam, 2006). This law also legalized the provision or exchange of needles and syringes (NSP) for people who inject drugs; this had previously been piloted on a small scale in Vietnam, but was officially illegal and conflicted with the Law on Drug Control. While the law indicates movement toward a more rights-based approach to HIV policy in Vietnam, there is evidence that some elements of the law were strongly encouraged by the international donor community, such as the element on needle and syringe programmes (Nguyen Ha et al., 2010) and that in 2010 there was still opposition to some of these measures at the local level (UNAIDS, 2010b).

A significant amount of money is spent on HIV prevention and care in Vietnam, with an estimated 102 million US dollars spent during 2009 (UNAIDS, 2010b). Of this, about 98% of the funding comes from bilateral and multilateral donor sources. This large dependence on donor funding has led to modifications in Vietnam's response to HIV and to the prevention and treatment priorities on the national agenda. For example, donor funding supports the vast majority of services providing needle exchange to injecting drug users and several pilot opioid substitution treatment programs, as well as the majority of antiretroviral treatment programs in closed facilities (prisons or mandatory re-education centers). Still, most of the funding provided by bilateral donors and by the Global Fund is focused on treatment and care, with relatively little allocated to prevention. No data were available for the amount of prevention funding from the Government of Vietnam that targeted key risk groups such as MSM, IDU, and sex workers (UNAIDS, 2010b).

Vietnamese culture and “social evils”

Even today, many important aspects of life in Vietnam continue to be influenced by Confucian practices, particularly that of ancestral worship. The worship of ancestors is important and practiced by most Vietnamese people. It is a sign of the close connection to generations that have come before and those that will follow. This continuous line between the generations makes marriage and reproduction of male offspring, in particular, very important in continuing the family bloodline (Belanger, 2006).

It is thought that individuals’ moral behavior passes on to their offspring and that this has a heavy influence on the fate of generations to come (Chanh, 1993). Strong social norms dictate behavior, and women, in particular, are expected to exhibit careful and virtuous behavior adhering to the Confucian “Four Feminine virtues” (*tu duc*) of attention to housework (*cong*), appearance (*dung*), speech (*ngon*), and conduct (*hanh*) (Binh, 2004; Go et al., 2002). Good upbringing, mostly by female relatives, teaches these virtues and they are a part of the overall sentiment or feeling of *tin* *cam* which, if practiced by a woman, will bring honor, harmony, and happiness to her family and to the family of her husband once she marries (Binh, 2004; Hong et al., 2004; Rydstrom, 1998).

Today in Vietnam, women both participate in the workforce, and also maintain primary responsibility for family life and family harmony (Werner, 2004). Communication about issues of sexuality between women and men, even when married, are typically limited (Ha, 2008). Women belong primarily to the husband’s family after marriage, with the husband and family-in-law guiding or making decisions related to the couple’s family life, including decisions related to childbearing (Drummond & Rydstrom, 2004). In Vietnam, women often live with their in-laws after marriage, especially in rural settings, while in urban Vietnam the married couple sometimes lives separately from the husband’s parents.

Contemporary Vietnamese culture continues to adapt to the effects of the 1986 “*Doi Moi*” reform (Drummond, 2006; Ha, 2008; Phinney, 2009). Following the introduction of the market economy policy, more cafes or nightclubs have appeared, and there is some evidence that there are more social spaces and opportunities for men, in particular, to engage in extra-marital sexual relationships (Phinney, 2008). The *Doi Moi* policy has been accompanied by a public perception of increased societal violence, drug use, and other vices, and this may have given rise to the government rhetoric and campaign around “social evils” which began just after the renovation policy (Rydstrom, 2006). Feelings of a more morally polluted world led to government campaigns against, for example, commercial sex venues during the late 1980s and 90s. A view of female sexuality was polarized with the ideal of the virtuous, family-oriented woman as detailed in the 1986 Law on Marriage and Family Life, which promotes women’s primary role as that of motherhood, responsible for the upbringing of moral children (Phinney, 2008; Rydstrom, 2006).

Not unlike many other places, the behaviors of drug use and sex work are heavily condemned both by societal and legal structures as well as by general community opinion in Vietnam (Hong et al., 2004; Khoat, Hong, An, Ngu, & Reidpath, 2005). The division of government that deals with drug use, prostitution, and HIV is called the Department of Social Evils Prevention, and the language of referring to drug use and sex work as “social evils” is widespread in Vietnam (Brickley et al., 2008; Hammett et al., 2008; Rydstrom, 2006; Thi et al., 2008; Vijayarasa, 2010). When apprehended by police, drug users and sex workers face mandatory 1-2 year interment

in rehabilitation centers termed “05/06 centers” (the numbers 05 and 06 come from the numbers of the government decisions to establish the centers in 1996). Thus far, these centers are dismal in their actual rehabilitation effect with > 80% of persons leaving the centers returning to their previous drug use and sex work behaviors (Center for Strategic and International Studies [CSIS] HIV/AIDS Task Force Delegation to Vietnam, 2006).



**Anti-drug use messages which closely link HIV and heroin use
(photo credit: UNAIDS 2011)**

HIV-related stigma in Vietnam

Stigma has been evidenced in Vietnam, as in other regions, within the health care setting through refusals to treat patients with HIV, in discriminatory or very negative treatment by health staff, in breaches of confidentiality related to patients' HIV status, and in performing HIV testing or disclosing HIV test results without patients' knowledge or consent (K. T. Hong et al., 2004; ICRW, 2010; Khoat et al., 2005; Thi et al., 2008). HIV-related stigma has also been documented within workplaces, communities, and families in Vietnam, in which PLHIV have reported being isolated in casual household contacts or being shunned and avoided by neighbors or others in the community (Brickley et al., 2008; K. T. Hong et al., 2004; Thi et al., 2008). It has been suggested that fears of HIV-related stigma and its sequelae lead PLHIV to keep their status secret from persons outside of, and sometimes within, the family (Brickley et al., 2008; Thi et al., 2008). Fears of stigma and discrimination have also been described as leading to internal stigma, self-isolation and low perceived quality of life among PLHIV, including non-disclosure of HIV status and avoidance of contacts with support networks and health care services (Gilbert & Walker, 2010; Greeff et al., 2010; Thi et al., 2008).

SUMMARY OF THE BACKGROUND TO THIS THESIS

HIV is no longer a “new” health problem, rather one that is thirty years old. Greater understanding of the epidemiology of HIV has led to a focus on high coverage of prevention in concentrated epidemics, with testing among key risk groups such as IDU, sex workers, and men who have sex with men.

Globally, progress has been made in HIV prevention, and still more advances have been made in HIV treatment. Current trends point toward improved outcomes and greater prevention if people test and start treatment for HIV earlier and adhere to treatment regimes.

Since the early days of the HIV epidemic, stigma has been recognized as strongly linked to HIV as well as to the behaviors of key risk groups that are heavily affected by HIV. Paradoxically, little progress has been made to concretely reduce the understanding and reduction of stigma over the course of the last thirty years.

Vietnam is a country with a fairly well-controlled concentrated HIV epidemic, but there is potential for rapid acceleration of HIV transmission if the appropriate prevention and care measures are not applied and scaled-up. There is evidence of high-risk behavior among large portions of key populations, with a significant level of sexual mixing between key populations and persons from lower risk groups. Population-level studies have demonstrated low risk perception, low HIV testing, late presentation for HIV treatment, fear-based HIV prevention messaging, and punitive rather than structurally rehabilitative policies for key populations. These perceptions and practices limit the effectiveness of prevention and care strategies.

This thesis will elaborate on the ways in which HIV-related stigma affects HIV prevention and care in Vietnam, both for those persons who express stigma and for those who are the recipients of HIV-related stigma. Through greater understanding of the mechanisms of HIV-related stigma, HIV prevention and care efforts can be made more effective in controlling the spread of HIV in Vietnam.

AIMS

OVERALL AIM

The overall aim of this thesis is to analyze and explore how HIV-related stigma influences HIV prevention and care in a concentrated HIV epidemic context.

SPECIFIC AIMS

Articles I and II focus on community members' views towards persons living with HIV and behaviors in relation to HIV testing. More specifically, these articles sought to:

- Identify factors associated with HIV-related stigma among community members (Article I)
- Identify determinants of HIV testing in a rural Vietnamese population (Article II)

Articles III and IV were conducted with persons living with HIV in relation to coping and treatment adherence. In particular, these studies aimed to:

- Explore how women living with HIV cope with HIV-related stigma (Article III)
- Explore factors influencing adherence to antiretroviral therapy among persons living with HIV (Article IV)

POINTS OF DEPARTURE

METHODOLOGICAL POINTS OF DEPARTURE

I employed both quantitative and qualitative approaches within this thesis and the way that I apply these approaches represents different research paradigms and distinct ways of viewing the nature of reality and of examining how truth exists and can be understood.

A great deal of the tradition of formal scientific inquiry has its roots in the positivist tradition which is usually typified by a belief that there is a single reality, that objective knowledge exists, and that knowledge can be gained through direct observation or experience (Bowling, 2002). In the positivist tradition the knower and the “known” are seen as independent and observations made are thought to be value-free facts (Bernard, 2000; Bowling, 2002; Robson, 2002). Stemming from the influence of Karl Popper in the 1950s, the post-positivist tradition arose as a reaction to positivism, upholding that research is, indeed, influenced by researchers’ values and, therefore, the best way to approach knowledge generation is to build up, systematically test, and disprove hypotheses so that through the refutation of what is observed *not* to be true, knowledge might be deduced (Bowling, 2002). Public health knowledge often rests on the (post)positivistic assumptions from the field of epidemiology, and seeks to find causal links between exposures and outcomes. This can be a useful approach when testing a clear hypothesis, particularly when attempting to generalize to a larger population.

While positivistic assumptions are often taken for granted as the main way of understanding reality and generating scientific knowledge in the medically-focused clinical sciences, other disciplines challenge these assumptions, particularly the disciplines of nursing and some of the social sciences (Robson, 2002), where the naturalistic approach is often found more useful. The naturalistic paradigm is more often associated with the qualitative tradition and accepts that there are multiple realities, each dependent on the viewer and the context, and that that these cannot be objectively measured, but rather described and understood through the researcher’s engagement with the research subject (Lincoln & Guba, 1985). Much of this approach stems from later nineteenth and twentieth century philosophical thought rooted in phenomenology, where individuals are believed to assign meaning to perceptions and situations based on interactions with each other in unique contexts (Bowling, 2002).

The research in this thesis has been shaped by positivistic and naturalistic paradigms, with the first two studies drawing on a population-based sample and applying quantitative reasoning and the second two drawn from a qualitative sample, which sought to understand and explore the realities as they were described by interview and focus group discussion participants.

Overall, when putting the studies together in this thesis, it is probably the case that the naturalistic tradition informs the approach to a greater extent. The implicit assumption that I have held while conducting this research, on a topic as multi-faceted as HIV-related stigma, is that many realities

can and do exist and that the truth in question is dependent on the eyes of who is observing and examining the situation. Reality has seemed still more complex when examined at the level of individual, family, and society, where human beings and family and societal systems concurrently and uniquely perceive, react to, and create reality, which is ever-changing. Within this thesis, I took the perspectives of multiple actors into account and solicited their views in open interviews, focus group discussions, and structured interviews. I have examined the issue of stigma from the perspectives of people living with HIV as well as from the perspective of those who are presumed to be HIV-negative, with a main focus on trying to understand the barriers to HIV care and factors that enhance HIV risk. Acknowledging multiple perspectives and multiple truths, allows for greater understanding of the societal factors that may enhance stigma against powerless individuals in society, serves as a strength that enables the issue of HIV-related stigma to be examined more thoroughly, and provides insight into how stigma might be understood and addressed at multiple levels.

A CONCEPTUAL FRAMEWORK

When Earnshaw and Chaudoir published their HIV Stigma Framework (HSF) in 2009, I had collected the data for the studies in this thesis and was already in the midst of data analysis. I read the article with interest and mixed feelings. I saw the framework as helping to clarify the conceptualization as well as measurement of individual-level processes of stigma and stigmatization (Figure 1). Also, I saw it as bringing new knowledge to the field in its focus on how stigma is experienced by PLHIV, as well as by those who are not HIV-infected and on how stigma processes impact individual-level behavioural outcomes differently for those who are and are not living with HIV. I also saw the HSF as filling an important gap within the HIV stigma literature because it separates stigma mechanisms and outcomes. In the HSF, stigma mechanisms and outcomes are recognized both for those who are living with HIV and for those who are presumed uninfected with HIV. Although the mechanisms and outcomes are presented as separate processes for HIV-positive and HIV-negative individuals, these processes are presented in the framework as impacting the other group, so that outcomes of HIV-stigma among HIV-negative individuals impact the mechanisms of stigma for persons living with HIV.

While the strengths of this framework have allowed me to see new connections within the different elements of the data I collected, I also saw some areas in which my empirical research in Vietnam did not seem to fit closely with the framework. I present the framework here as one possibility to conceptualize some of the elements covered within this thesis, and will come back to it in the discussion, in order to discuss it as a possible explanatory framework and to reflect on its strengths and weaknesses in relation to my empirical research. I will also suggest some modifications to the HSF, based on results from my studies and the application of the framework in the Vietnamese context.

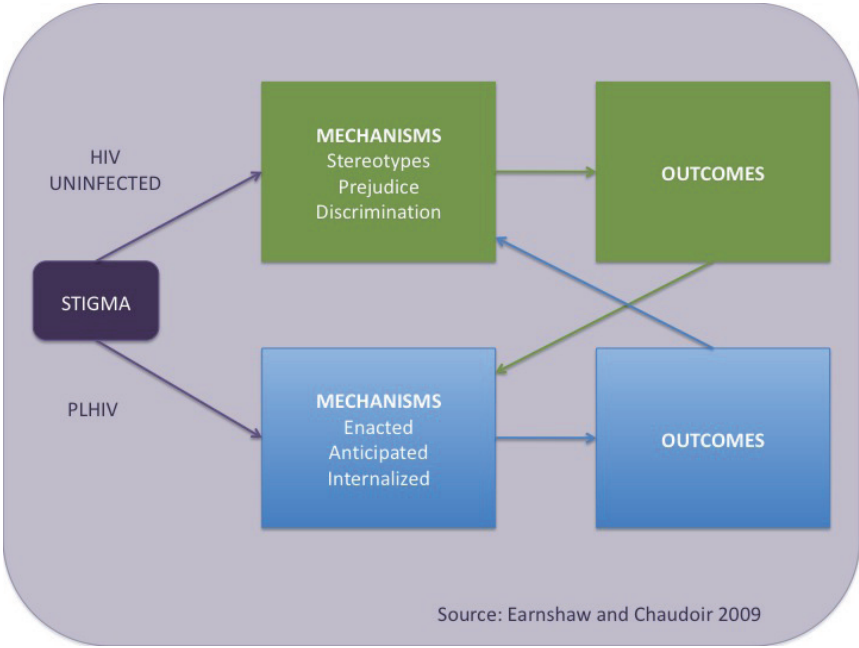


Figure 1: HIV Stigma Framework

MATERIALS AND METHODS

OVERVIEW OF STUDY DESIGN

In order to address the research questions presented as part of the study aims, this thesis consists of three studies (A-C), which correspond to four articles (I-IV). Study A consists of articles I and II, while study B consists of article III and study C of article IV (see Table 2).

Table 2: Overview of study design

Study	A		B	C
Article	I	II	III	IV
Research question(s)	What are the factors associated with different levels of HIV-related stigma among community members?	What are the determinants of HIV testing in a rural Vietnamese population?	How do women living with HIV cope with the effects of HIV-related stigma?	What influences ART adherence among PLHIV in Vietnam?
Study setting	Bavi district, Filabavi DSS		Peri-urban Hanoi area	Quang Ninh province
Design	Population-based cross-sectional survey (quantitative)		Interview study (qualitative)	Group interview study (qualitative)
Study population	1874 adult males and female		12 women with HIV	48 adults (31 males and 8 females with HIV; 5 male and 4 female family members to PLHIV)
Data collection method	Structured interviews		Qualitative interviews	Focus group discussions (7)
Analysis	Latent class analysis; Latent class regression	Univariate analysis; Multivariate logistic regression	Interpretive description	Manifest and latent content analysis

Article I is a quantitative study that identifies factors associated with HIV-related stigma through structured interviews among Vietnamese rural adults.

Article II is a quantitative study that evaluates the determinants of HIV testing in a rural Vietnamese population through structured interviews among Vietnamese rural adults.

Article III is a qualitative study that uses in-depth interviews with adult women living with HIV to explore how they cope with HIV-related stigma.

Article IV is a qualitative study that uses focus group discussions with persons living with HIV and some of their family members to understand factors influencing adherence to antiretroviral therapy.

Studies within this thesis use qualitative and quantitative data collection and analysis methods, with the choice of method based on the research question. Structured questionnaires, qualitative interviews, and focus group discussions are used.

STUDY SETTINGS

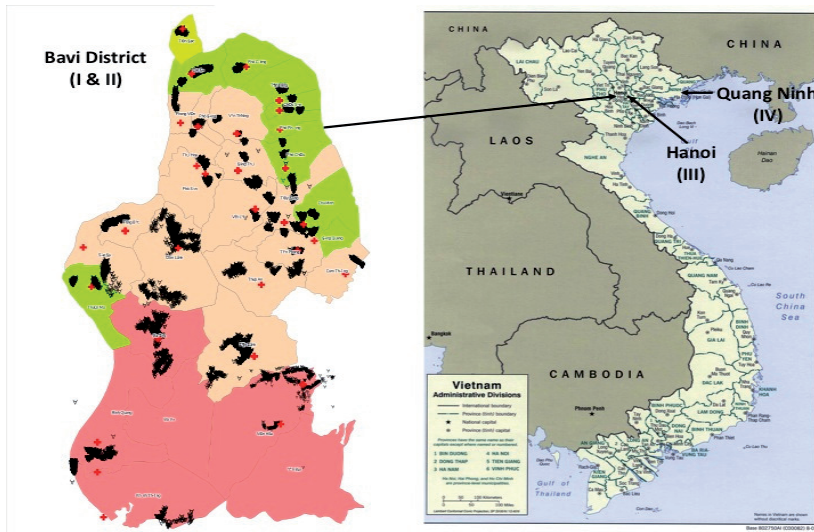


Figure 2: Map of Vietnam, including the Study Areas

The studies included in this thesis were conducted in three different areas in the northern part of Vietnam: Bavi district, Ha Tay province (study A); the peri-urban area of Hanoi city (study B); and Quang Ninh province (study C) (see map in Figure 2). At the time that the studies were conducted in 2007, Ha Tay was a province on its own. In 2008, it was incorporated into Hanoi province. For the purpose of this thesis, Ha Tay province will be referred to, as will the existing provincial structures that were in place at the time of data collection.

Bavi District (study A) is a largely rural farming district, although some parts of the district are just 60 kilometers to the northwest of Hanoi city. It takes about 90 minutes to drive between central Hanoi and Bavi district, on a well-paved road. Due to its proximity to Hanoi, some parts of the district attract urban residents to vacation at holiday resorts or to visit temples. The district is in the highly fertile Red River delta area, and more than 80% of economic activity centers around farming, mostly of labor-intensive crops such as rice, cassava, soybeans, and some assorted fruits and vegetables. Bavi district is also well-known in the surrounding provinces for its milk production. In addition to farming, some economic activity centers around forestry and small trade. The district is comprised of about 262,000 persons (2007 population estimate), 91% of whom are from the main Kinh ethnic group (Chuc & Diwan, 2003). The district contains four geographical areas including highland, lowland, mountainous, and island areas. The mountainous areas are the

most remote, and some of the highland areas are closer to the main road and other district services. A small proportion of the population live on islands on the two rivers that border the district. In total, these geographical areas are spread between 32 different communes, including one small town, where the 150 bed district hospital is located. There are also 3 regional polyclinics in the district, 32 communal health stations and about 200 assorted private drug sellers and practitioners (Chuc & Diwan, 2003).

Table 3: Basic HIV Indicators for Vietnam and by study area

	Bavi	Quang Ninh	Hanoi	Vietnam	Source
Estimated HIV prevalence, percent of adults 15-49 (2010)	0.46*	0.99	0.84	0.44	(Ministry of Health Vietnam, 2005; UNAIDS, 2010a)
Estimated number of IDU	-	1191-571	15,777-37,864	111,233-273,561	(Ministry of Health Vietnam, 2009)
Estimated number of female sex workers	-	300-900	1600-4800	29,059-84,477	
Estimated HIV prevalence among IDU (2010), %	26.3 *	55.8	32.9	30	"
Estimated HIV prevalence among CSW (2010), %	13.8*	2.8	12.3	9	"
Estimated HIV prevalence among MSM (2010), %	-	-	3.8	2	"
Estimated HIV prevalence among clients of sex workers (2010), %	1.7*	4.3	3.1	2	"
ART coverage, percentage of those needing ART receiving it based on WHO 2010 guidelines (2009)	-	-	-	33	(UNAIDS, 2010a)
Female:male ratio of HIV-positive persons	-	-	-	0.36	(Ministry of Health Vietnam, 2009)
Women as a percentage of total persons receiving ART (2009)	-	-	-	28	(UNAIDS, 2010a)

* Estimate for the entire Red River Delta region, no estimate available for Bavi district



The irrigation and processing of rice crops in Bavi District, Vietnam

HIV testing services have been available at Bavi district hospital since about 1998 and cost about 30,000 Vietnam Dong (US \$1.80) out-of-pocket in 2006. The reported HIV rate in Bavi district in 2007 was 0.12%, based on a district surveillance system of data on all reported HIV positive cases. However, no accurate HIV prevalence estimates exist (Personal communication, Bavi District Preventative Health Director, 25th Sept 2008).

Hanoi (study B) is the political capital of Vietnam and is a large urban setting with about 3.3 million inhabitants (prior to 2008, when Ha Tay province was joined with Hanoi, thereafter making it Vietnam's largest northern province with 6.5 million inhabitants)(General Statistics Office Vietnam, 2010). The province of Hanoi contains many peri-urban and remote areas in the city's outskirts, where rice farming is conducted and which house a myriad of factories. It is common for persons from other provinces throughout Vietnam, particularly those in the surrounding areas of northern Vietnam, to migrate for work to Hanoi on short or longer-term bases. A very wide range of public and private health services are available in Hanoi, and this is the location of the national referral hospitals for HIV and the seat of all government and most non-government national HIV programs and activities. The HIV prevalence in Hanoi was estimated at 0.84% in 2010 (Ministry of Health Vietnam, 2005). Antiretroviral therapy started to be available in Hanoi in 2005. Many patients travel to Hanoi for HIV testing and care from the surrounding rural provinces because services are more easily available there, and also out of fear of the disclosure of one's HIV status when seeking HIV services in the less anonymous rural areas.

Quang Ninh province (study C) is in Northeastern Vietnam, about 150 kilometers from Hanoi. Quang Ninh is the province with the highest HIV prevalence in Vietnam, with about 1% of the adult population estimated to be HIV-positive (Ministry of Health Vietnam, 2005). The spread of HIV within Quang Ninh is thought to be driven by injecting drug use, the trafficking of drugs through the province, and tourism and trade through Quang Ninh's famous seaport at Halong City. Quang Ninh also has an extensive coal mining industry and many persons migrate to the province to work in the mines as well as to work within the cement and fishing industries. The population of the province is 1.15 million, and the province consists of 12 districts and two cities that comprise 182 communes.

Basic preventative and health services are available at commune health stations and at district hospitals. The provincial hospital, two hospitals operated by the coal mining industry, the TB hospital in Ha Long City, district preventative health centers and district hospitals all provide rapid HIV testing but not confirmatory testing. Confirmatory tests and other more advanced health services are available at Uong Bi General Hospital and at the provincial preventative center (General Statistics Office Vietnam, 2010). Antiretroviral therapy started to be available to a handful of patients in this province in 2005. As of November 30, 2010, 3521 patients were receiving ART in Quang Ninh (personal communication, Quang Ninh Provincial AIDS Center, 31 Dec 2010).

PARTICIPANTS, DATA COLLECTION, & ANALYSIS

Articles I & II

Participants and data collection: Articles I & II

Within Bavi district, the study resulting in articles I & II were carried out within the framework of the demographic surveillance site (DSS) Filabavi (hereafter referred to as Filabavi), which has been

operating in Bavi district since 1999. Demographic surveillance sites are often used to generate data for health planning and policy making in areas where reliable vital registrations systems are non-existent (Chuc & Diwan, 2003). Since 1999, heads of Filabavi households have been surveyed quarterly on vital events that have taken place within the household, with specific attention to pregnancy, birth, migration, and death events. Every two years, a re-census of the population is carried out and additional information, such as household economic status and education level, are gathered. All surveys are done through face-to-face interviews with structured questionnaires in Vietnamese by a group of 46 trained female surveyors who have completed at least secondary school. There are six medically-trained field supervisors and one field coordinator who supervise data collection. Quality assurance is carried out through weekly meetings with the surveyors and by reviewing all data that is collected within the DSS. As an additional mechanism for quality assurance, field supervisors conduct re-interviews of about 5% of the home visits.

In order to draw the sample for Filabavi, the entire district (population approximately 262,000) was divided into 352 population sampling units, or clusters. A cluster is typically defined as an administrative unit, most often a village. On average there are approximately 160 households and 670 persons per cluster, although sizes vary. Twenty percent (about 69) of the clusters were then randomly sampled, with probability of selection proportional to the population size of the cluster. These 69 clusters thus formed the basis of the Filabavi DSS sample at its inception in 1999. In 2007, two additional semi-urban clusters were added to the DSS sample to try to make the DSS more representative of the district, which had become slightly more urbanized since the DSS's inception. The total population of the DSS was 50,456 individuals who made up about 12,818 households (2007 population numbers).

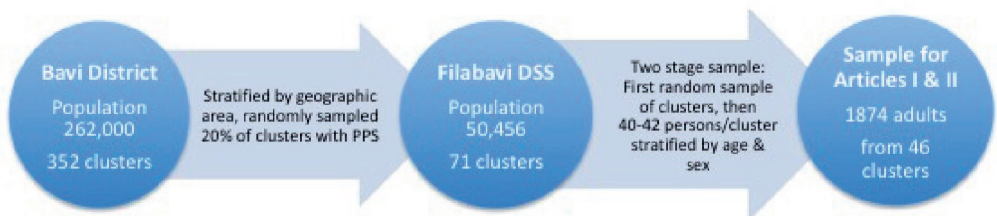


Figure 3: Sampling for study A (articles I & II)

For study A, a sub-sample from the DSS population was drawn (articles I & II). We conducted a two-stage cluster sampling (see Figure 3). First, 46 of the 71 clusters were randomly selected. Then, 1874 adults (18-60 years), stratified by age and sex, were selected from within the 46 clusters. The sample size was calculated so that we could obtain 95% confidence intervals not wider than 2.25% units for a variety of outcome measures (since the estimated percentage of these outcome measures varied, we set the estimated percentage for the sample size calculation at 50%). Simple random sampling was not feasible at the level of individuals due to timing constraints. In order to carry out the sampling of individuals, surveyors first randomly selected one of the six strata (male/female and three age strata each) and, then, selected a person from that strata from the first household visited in one cluster. If no one matching the gender and age criteria was present at that household, or if the sampled individual refused to participate, a replacement was sought at the next household visited. Individuals were sampled in turn from each of the six strata until the sample from that cluster (42 individuals) was complete. Basic demographic and descriptive information about the study sample can be found in article I, Table 1.

A structured questionnaire was used to collect data for study A. Structured questionnaires are very commonly used research tools with health research and beyond. Structured questionnaires are composed of mostly closed questions that generate data that can be analyzed quantitatively for trends and patterns. Within structured questionnaires, composition and ordering of questions is predetermined by the researcher and does not allow for flexibility whereby the respondent might qualify or expand upon their answers (Bowling, 2002). The disadvantage of structured questionnaires is that respondents' answers might be "forced" into pre-determined categories that don't fully qualify or explain their answers. The structured questionnaire used to collect data for study A (see Appendix I) was administered face-to-face by trained interviewers and it included questions about HIV-related stigma, knowledge, attitudes, and past HIV testing. In some cases, respondents were given an open question such as "How can HIV be transmitted?" and they were asked to respond in their own words about all of the ways that they thought HIV could be transmitted. The responses were then coded by the interviewer into pre-determined categories. The stigma questions were developed based on the concepts of stigma presented by Link and Phelan (2001) of labeling, stereotyping, separation, status loss, and discrimination—all items which were theorized to lead PLHIV to be less open about their HIV status and to inhibit them from seeking preventative, testing, and/or treatment services. The items included have also been used in common stigma scales (Genberg et al., 2008; Kalichman et al., 2005; Link & Phelan, 2001). From these, statements about persons living with HIV were asked with possible responses, "Yes", "No", or "Not sure/maybe".

The questionnaire was pre-tested and revised prior to training surveyors and commencing data collection. The individual selected to be interviewed was given information about the study and interviewed in person if s/he consented to participate. Very few refusals to participate occurred, with only two being recorded. Data collection took place between April and June 2007.

Data analysis: Article I

STATA version 9.0 (College Station, Texas, USA) and the poLCA package (Linzer & Lewis, 2007) for the open-source software R version 2.10.1 (R Development Core Team, 2009) were used for data processing and analysis. Household socioeconomic and migration data collected during regular DSS rounds since 1999 were linked to the individuals in this survey.

The following variables were generated during data analysis for article I:

Long-term outmigration: A dichotomous variable for long-term outmigration was calculated for having left (and returned to) the district for greater than three months at least one time during the 7 years prior to the study.

Heard of HIV from more sources: A dichotomous variable for "heard of HIV from more sources" was created for spontaneously listing 3 or more sources from which the respondent had heard of HIV.

Economic status: calculated based on principal components analysis of household assets and dichotomized into the top 40% and bottom 60% of the study sample (Rutstein & Johnson, 2004).

Feels at-risk for HIV: was based on an affirmative answer to the question "Do you think that you are personally at risk for getting HIV, the virus that causes AIDS?"

Knows someone with HIV: was based on an affirmative answer to the question “Do you know anyone who is infected with HIV or who has died of AIDS?”

Descriptive data analysis was conducted first in order to understand frequencies of the socio-demographic variables, HIV risk variables, and the stigma statements. T-tests were used to determine significant differences between groups for continuous variables such as age or number of stigma statements endorsed. Pearson’s Chi-square test was employed to investigate statistically significant associations between the individual HIV stigma statements and relevant socio-demographic and HIV risk variables. Thereafter, using the set of categorical responses (“Yes”, “Not sure/maybe”, or “No”) to the eight stigma statements, latent class analysis was performed to organize respondents into meaningful groups based on the stigmatizing attitudes that they expressed about persons living with HIV.

We determined an underlying latent class structure for HIV-related stigma, using the criteria of minimizing the values for Akaike Information Criteria (AIC) and Bayesian Information Criteria (BIC), both of which compare the parsimony and fit of different latent class models. In addition to AIC and BIC minimum values, we examined the practical and theoretical usefulness of the final class structure (Collins & Lanza, 2010). In our analysis (see Table 2, article I), the AIC and BIC values for the three- and four-class solutions were very similar, and after examining both solutions, we chose the three-class solution as we judged it more practically and theoretically useful for public health application. We then evaluated correlates of latent class membership with latent class regression. A multinomial logistic regression model was constructed to identify factors independently associated with the dependent variable: stigma group (or class) membership. The least stigmatizing group was chosen as the reference group. Independent variables significant in bivariate analysis with at least one of the eight stigma statements at a level of $p < 0.10$ were included in the model using a stepwise forward selection procedure. Interaction was checked for between variables in the model and no significant interaction was found. The best regression model was assessed by minimizing the Chi-square goodness of fit (Linzer & Lewis, 2007). Odds ratios with 95% confidence intervals were computed. A value of $p < 0.05$ was considered statistically significant in the final model.

Data analysis: Article II

STATA version 9.0 (Stata Corporation, College Station, TX, USA) was used for data analysis. The data collected in this survey were linked to household socioeconomic, pregnancy, and migration data for the DSS cohort.

The following variables were generated during data analysis for article II:

Economic status was determined by principal components analysis (PCA) for household assets and dichotomized into the poorest 60% and the least poor 40% (Rutstein & Johnson, 2004).

Place of residence: This was classified based on geographical area based on the DSS classifications of highland, lowland, mountainous, and island. We dichotomized into the more urbanized highland area and the less urban non-highland areas (including mountainous, lowland, and island areas).

Long-term migration: was defined as having left the district for 3 months or more during the 7 years prior to the survey; those who had not left or migrated for shorter than 3 months were classified as non-migrants.

Recent pregnancy: Women aged 18 to 45 years were classified into recently pregnant (those who had been pregnant, regardless of pregnancy outcome, during the 3 years prior to data collection or who were pregnant at the time of data collection) and not recently pregnant (women aged 18 to 45 who had not been pregnant during the three years prior to data collection).

In order to test the differences in the only continuous variable used (age), we applied t-tests. In order to test for associations between HIV testing and other categorical and dichotomous demographic and HIV risk variables, we used Pearson's Chi-square and odds ratios with 95% confidence intervals. HIV testing rates for men and women were age-adjusted for the population structure of 18-60 year olds for the entire DSS sample based on 2007 population numbers. We constructed a multivariate logistic regression model in order to identify factors that were independently associated with the dependent variable: HIV testing. The independent variables that were significant in bivariate analysis at a level of $p < 0.25$ were included in the model and removed using a backwards stepwise method. We tested all independent variables for interaction and only one interaction term involving two variables – “feels at risk for HIV” and “plans to test for HIV in the coming year” – was statistically significant and included in the final model. We tested the model's goodness-of-fit using the Hosmer-Lemeshow method and by examining receiver operating characteristic (ROC) curve plots (Hosmer & Hjort, 2002). The final area under the ROC curve was 0.829, meeting criteria for good model discrimination (Lemeshow & Hosmer, 1982).

Article III

For study B (article III), we wanted to explore how individuals coped with HIV-related stigma. Our research question was open and not highly-defined prior to the outset of the data collection and, therefore, we decided that a qualitative approach was most suitable.

We conducted qualitative interviews (sometimes also referred to as “in-depth” or “unstructured” interviews) which is a method used to try to elicit an individual's in-depth views on a topic or description of a lived experience (Dahlgren, Emmelin, & Winkvist, 2004). Qualitative interviews are most often conducted face-to-face and typically involve one interviewer and one interviewee, although variations exist. The interviewer may have a list of pre-determined questions or may focus the interview around one broad opening question and then conduct follow-up probing questions based on what the interviewee discusses. The strength of qualitative interviews is that they allow for the discussion of sensitive topics and detailed description of life experience. The disadvantage to using this method of data collection is that it can be time-consuming to collect data and it requires a highly skilled interviewer (Dahlgren et al., 2004). We used qualitative interviews in order to explore the experiences and challenges of women living with HIV in coping with HIV-related stigma. The interviewer used a question guide with general themes; these were reviewed and adapted after each interview to include content from the ideas that had been highlighted in the previous interview.

To identify study participants, my co-researcher (a young Vietnamese woman with interview experience) and I contacted women living with HIV through organizations and clinics for PLHIV based in Hanoi. We introduced ourselves as university-based researchers who wanted to learn more about life situations for women living with HIV. All of the twelve women who we invited to participate in the study agreed to take part in face-to-face interviews. We purposively sampled women with more and less recent HIV diagnoses and women in different phases of life and with

different attributes that might affect their experience in living with HIV (younger and older age, living with and apart from in-laws, with and without children, living within and outside of the city). We judged that the sample size and variation was sufficient to obtain a meaningful description of the study phenomenon, while still being feasible within time and resource constraints (Thorne, 2008).

Data were collected between April and July 2007 in Northern Vietnam. Interviews were carried out at the location of the interviewee's choosing. Prior to starting the interview, informed consent was verbally obtained from the participant after explaining the study's purpose and answering any questions that the participants had about the study. Interviews lasted between one and two hours and were digitally recorded, with the participants' consent. Interviews were conducted in Vietnamese by a trained female interviewer.

An interview guide of open-ended questions based on general themes with specific probes was used (see Appendix II). We also allowed the participants to introduce topics of interest, and some participants did this during the interviews. The interview guide was revised after discussion among the research team following each interview and probes were refined to further elucidate and test emerging concepts. During the interview process, field notes were kept of impressions related to the interview and of the content of discussions among the team members. The interviews were transcribed into Vietnamese and then translated into English. Back-translation into Vietnamese was carried out on selected parts of the text, as well as later during the process of analysis to check whether meaning was correctly captured. The texts were read through and corrected for errors, going back to the original Vietnamese recordings when needed.

Data analysis: Article III

Interpretive description was used to guide the analysis, as we wanted to explore how women living with HIV cope with the HIV-related stigma that they experienced. Initially, we had planned to use content analysis for this study, but after beginning the analysis process, the steps of condensing the codes into meaning units, and building up codes into categories and themes seemed overly-prescriptive for the data, not allowing the many inter-relationships between coded concepts to be adequately explored (Graneheim & Lundman, 2004). Since we wanted the results to be relevant to clinical and public health practice, we chose interpretive description as the methodological orientation for the study design and analysis (Thorne, 2008; Thorne, Kirkham, & MacDonald-Emes, 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). Interpretive description is characterized by a stringent, but not prescriptive, process of inductive data analysis (Thorne, 2008). Interpretive description draws on principles of social science and connects them to clinically-derived disciplines so as to be meaningful in the practice setting. The inductive approach worked well since we did not have strong theorized relationships about concepts when we started the study.

The data, consisting of the interview texts, was manually coded separately using an inductive coding process. Thereafter, each interview and its codes were discussed, with discussion notes taken. Codes were placed into groups that appeared to be related and the contents and relationships between codes were discussed among the entire research team. Continued analysis involved a rigorous process of going between the interviews, the codes, discussion notes, field notes, and relevant empirical and theoretical literature on stigma, HIV, and gender in Vietnam (see Figure 1, Article III for an example of analysis process). Particular attention was paid to documenting how latent, or interpreted, meaning was derived from the text. The codes and the relationships between

them were organized under a central theme. Preliminary findings were repeatedly discussed among the research team and compared against the individual interview cases to ensure that the interpretive analysis remained relevant to the individual cases. Analysis ended when the research team had come to an agreement about the content within and relationships between codes and the theme and when these were judged applicable to the interview cases.

Article IV

The research team for article IV consisted of five persons with backgrounds in nursing, medicine, and public health. We wanted to explore factors that influenced adherence to antiretroviral therapy for patients living with HIV. To do this, in October 2006 we selected study participants for focus group discussions from the group of seventy patients (at the time) who were receiving ART at the outpatient clinic of Uong Bi Hospital and residing in Quang Ninh province.

Focus group discussions (FGDs) are a commonly used qualitative method within health and behavioural research. They usually take the form of semi-structured group interviews which are conducted in order to provide in-depth understand of a variety of participants' views on an issue. FGDs make use of the group dynamic and, thus, tend to highlight community norms and dilemmas. Focus groups are not usually used as a forum for discussing individuals' experiences of sensitive topics. FGDs are typically led by a trained moderator who facilitates the discussion, introducing topics and monitoring conversation flow according to a pre-determined set of discussion questions or themes. A notetaker is often present to take note of non-verbal communication and group dynamics and conversation flow. A strength of the method is that it allows for the emergence of unforeseen questions or themes which arise during the discussion, while a disadvantage is that non-normative opinions or sensitive information might not come out in the group (Bowling, 2002). We used FGDs, which followed a discussion guide, with persons living with HIV and some of their family members in study C in order to examine what patients and their family members saw as barriers in adherence to antiretroviral therapy.

We used residence in the study province as inclusion criteria to make it logistically possible to participate in the focus group discussion. Among those patients living within the province, participants were purposively selected to get a variation of duration of time on ART, since we hypothesized that that challenges to adherence might change over time. We also thought it would be helpful to get the perspective of some family members (parents or spouses) who had been providing support to the patients during the course of their treatment. Family members were recruited through patient participants. Participants were contacted at the outpatient clinic or by telephone and given information about the purpose of the focus group discussions; those giving verbal consent to participate were included.

In total, there were forty-eight participants divided into 7 FGDs: four groups with male patients (n=24), one group with female patients (n=7), one mixed group with male and female patients (n=8), and one group with male and female family members (n=9). Patient groups were organized based on duration on ART (from two weeks up to seven months).

A discussion guide was developed in English, translated into Vietnamese and initially piloted in one FGD. Topics discussed included: major adherence obstacles encountered during ART, strategies for PLHIV to enhance ART adherence, support received from family members when taking ART,

suggestions for how to further improve adherence, and the feasibility of ART home delivery (see Appendix III). Probes were used to explore the topics more in-depth. FGDs were conducted in a private meeting room at the hospital outpatient clinic and lasted 90-120 minutes. Discussions were conducted in Vietnamese and were moderated by one of the co-authors, a medical doctor with extensive experience conducting qualitative interview studies as well as another trained FGD moderator, both native speakers of Vietnamese. All groups were observed and notes were taken regarding non-verbal communication and group interaction. The content of each FGD was recorded and transcribed verbatim. The identity of the speaker was dissociated from the transcript once the transcripts were finalized to ensure confidentiality. Transcriptions were checked against the recording to check the quality of the transcript.

Data analysis: Article IV

Manifest and latent content analysis were applied in article IV. Content analysis is a qualitative method which focuses on the presence of, meaning of, and relationships between concepts in text, emphasizing variation within and between what is described outright (manifest content) and underlying meanings (latent content) in the text (Graneheim & Lundman, 2004). We chose content analysis in order to understand meaning and variation of views regarding what influenced patients' adherence to ART outright, while allowing us to also look at underlying meanings. All the transcripts were read through a number of times until there was a sense of familiarity with the data. Coding and categorizing were performed manually and inductively, in stages. The first stage consisted of identifying meaning units, where phrases in the transcript were underlined and then restated in the margins as codes. From the codes, categories were developed and then further compared and merged into a theme (see Appendix IV for theme, categories and codes).

ETHICAL ASPECTS OF THE STUDIES

Ethical approval for studies A-C was obtained from Hanoi Medical University's ethical review board. Ethical approval for study C was also obtained from Karolinska Institutet's ethical review board. Local authorities in all settings gave permission to conduct the studies and all participants included in the studies gave verbal or written informed consent after the study was explained to them. It was stressed that they could withdraw from participation at any time, although no participant exercised this right during the course of our studies.

In the cases of several of the participants who we met for interviews for study B, there was a need for services or additional support in relation to their HIV infection identified through the course of the interview discussion. For example, one woman had no connection with medical care and was not receiving treatment for her HIV, for which she had tested positive four years prior. She did not know where to access care and asked if we could recommend a clinic to her. When we identified these cases, after the formal interview was finished, we offered to connect the participant to existing HIV care or support services. In all cases where this need was identified and offered, the participants consented to the referral and we accompanied them to the place of care or service as is customary when making a referral to services in Vietnam. We did not explain that this was a benefit of study participation when seeking consent to take part in the interview, but, rather, we judged that this was the most appropriate course of action when there was a need for HIV medication or additional social support.

MAIN FINDINGS

The findings are taken from the results for articles I-IV and also include some data that was not presented in the articles but which might further enhance understanding of the study aims. The findings are presented by themes, which sometimes incorporate results from two or more articles.

Overall, familiarity with HIV was high in the study population for articles I & II and, despite the rural and low HIV prevalence in the study setting, 41% of community members reported that they knew someone with HIV, while 90% reported that they believed HIV to be a problem in their community. Nearly all respondents (98%) reported having heard about HIV previously, mostly from television (92%), radio (42%), magazines or newspapers (24%), and friends or relatives (16%). Men were significantly more likely than women to have heard about HIV from TV, radio, and magazines, while women were significantly more likely than men to have heard of HIV from relatives or friends, or from government union-sponsored public health education campaigns. The mean number of sources from which men had heard about HIV was 1.91 ± 0.95 , while women listed slightly, but significantly fewer, sources 1.76 ± 0.93 ($p < 0.001$).

FACTORS ASSOCIATED WITH HIV-RELATED STIGMA (ARTICLE I)

As shown in article I and Figure 4, we found very high stigma towards PLHIV among adults living in rural Vietnam.

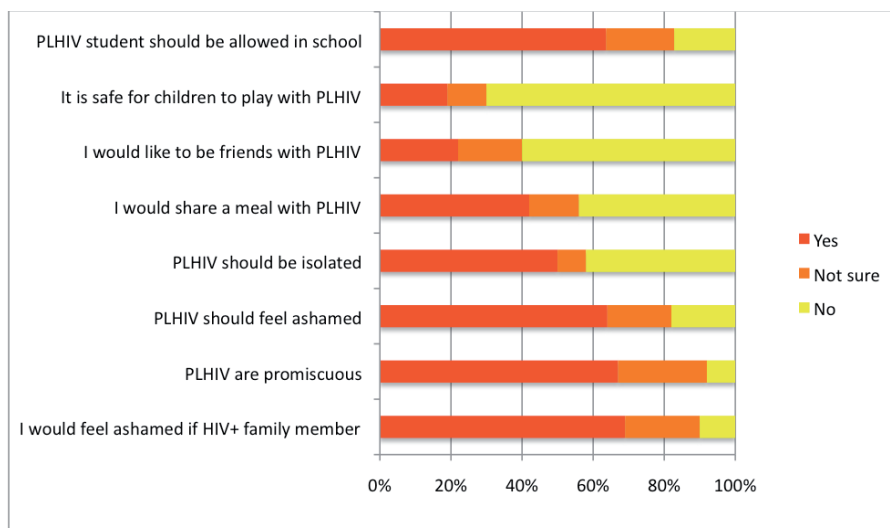


Figure 4: Stigma toward persons with HIV as expressed by Vietnamese rural adults ($n=1874$)

Overall, about 90% of all respondents of both sexes agreed with two or more stigmatizing statements about persons living with HIV; however, women were more likely than men to endorse stigmatizing statements towards persons living with HIV (significantly more women endorsed seven of the eight stigma statements). The mean (\pm SD) number of statements endorsed by women was 4.59 (\pm 2.14) while the mean for men was significantly lower (4.01 \pm 2.06, $p < 0.001$).

Using latent class analysis to find natural groupings among participants based on their responses to the stigma statements, we found that the study population was divided into three groups who attached varying degrees of stigma to persons living with HIV. These groups ranged from least to highly stigmatizing, and included a third group which we labelled ambivalent because its members were most likely to state that they were “unsure” or “did not know” in response to one of the stigma statements. The least stigmatizing group comprised about 43% of the population, while the highly stigmatizing and ambivalent groups comprised 38% and 19% of the population, respectively. Even in the least stigmatizing group, expressions of stigma were fairly high, particularly for the statements: “PLHIV should feel ashamed”, “I would feel ashamed if a family member had HIV”, and “PLHIV are promiscuous”.

Multinomial logistic regression confirmed the results of univariate analysis and indicated that women were more likely than men to attribute stigma to PLHIV (Table 4). Factors that were associated with less stigmatizing attitudes toward PLHIV were: greater educational attainment, a history of long-term migration out of the district, feeling at-risk for HIV, having heard of HIV from more sources, and knowing someone with HIV.

Table 4: Factors associated with stigmatizing attitudes towards persons living with HIV among rural Vietnamese adults

<i>Reference group is Class 1 (least stigmatizing)</i>	Class 2 Ambivalent aOR (95% CI)	Class 3 Highly stigmatizing aOR (95% CI)
Sex		
Male	1.0	1.0
Female	1.09 (0.79-1.50)	1.84 (1.42-2.37)**
Long-term outmigration		
No	1.0	1.0
Yes	0.84 (0.53-1.33)	0.61 (0.40-0.91)*
Education		
Primary	1.00	1.00
Secondary	0.78 (0.48-1.27)	0.45 (0.32-0.62)**
Tertiary	1.12 (0.60-2.09)	0.19 (0.10-0.35)**
Heard of HIV from more sources		
No	1.0	1.0
Yes	2.01 (1.41-2.88)**	0.44 (0.30-0.66)**
Feels at risk for HIV		
No	1.0	1.0
Yes	0.54 (0.33-0.90)*	0.42 (0.27-0.66)**
Knows someone with HIV		
No	1.0	1.0
Yes	0.32 (0.22-0.46)**	0.76 (0.58-0.99)*

Notes: aOR= adjusted odds ratio; data are reported as aORs adjusted by all other variables in the model.

* $p < 0.05$ ** $p < 0.001$

When examining what determined ambivalent class membership, surprisingly, it appeared that those who had heard of HIV from more sources had greater odds of belonging to the ambivalent group. Those who felt at-risk for HIV or who reported knowing someone with HIV had lower odds of belonging to the ambivalent group.

DETERMINANTS TO HIV TESTING IN RURAL VIETNAM (ARTICLE II)

We found low HIV testing in this rural population, with the age-adjusted prevalence of ever having tested for HIV being 7.6%, and with a slightly higher proportion of men (8.9%) having tested than women (6.4%, $p=0.073$). As might be expected, a higher proportion of younger persons reported having had an HIV test: 9.2% of 18-29 year olds compared to 4.6% of those ages 45-60. The 217 women who had been pregnant or recently given birth had a slightly lower HIV testing rate (6%) than the female non-recently pregnant population under 45 years of age (7.5%, $p=0.48$).

Needs for enhanced HIV testing were identified, with more than 75% of those who reported feeling at risk for HIV and 89% of those reporting knowing someone with HIV having had never been tested for HIV. Very few people reported plans for future HIV testing (3%). In a multivariate logistic regression model, factors found to be associated with past HIV testing were younger age, highland residence, higher income, out-of-district migration, having information about HIV, feeling at-risk for HIV, listing condoms as a method to prevent HIV, knowing someone with HIV, and planning to test for HIV again in the coming 12 months (see Figure 5 for adjusted ORs with 95% confidence intervals).

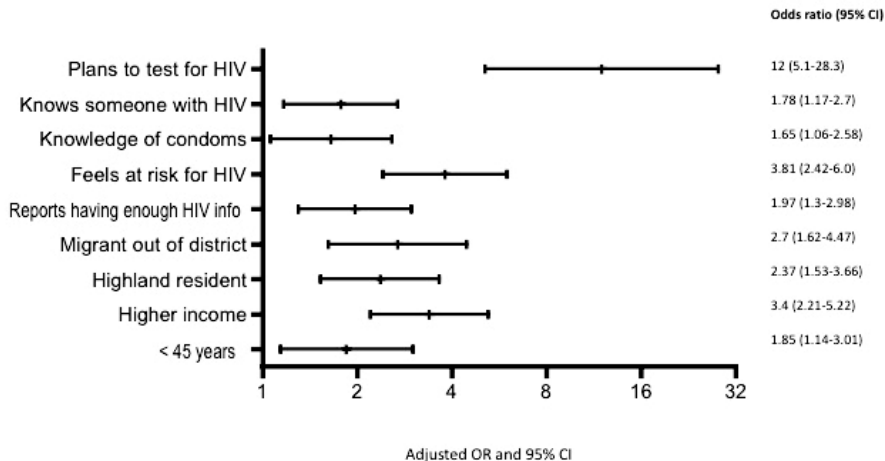


Figure 5: Adjusted odds ratios of determinants of having HIV tested among Vietnamese rural adults ($n=1818$)

HIV Testing and Stigma

Generally in this study population (study A), there was an inverse relationship between HIV testing and stigma towards persons living with HIV. Those who endorsed the stigma statements had lower

odds of having HIV tested and, for 6 of the 8 stigma statements, this relationship was statistically significant (see Table 5).

Table 5: Stigma mechanisms towards PLHIV by past HIV testing status among Vietnamese adults (n=1818)

	Never HIV tested n=1683 n (%)	HIV tested n=135 n (%)	OR (95% CI)
PLHIV should be isolated	869 (52)	40 (30)	0.39 (0.27-0.58)
I would be ashamed if someone in my family had HIV	1177 (70)	77 (57)	0.57 (0.40-0.82)
PLHIV are promiscuous	1135 (67)	86 (64)	0.85 (0.59-1.22)
PLHIV should feel ashamed	1098 (65)	65 (48)	0.49 (0.35-0.70)
I would not like to be friends with someone with HIV*	1005 (60)	65 (48)	0.63 (0.44-0.89)
I would not share a meal with someone with HIV*	755 (45)	39 (29)	0.50 (0.34-0.73)
It is not safe for children to play with PLHIV*	1184 (70)	80 (59)	0.61 (0.43-0.88)
A student with HIV who is not sick should not be allowed to continue school*	293 (17)	21 (16)	0.87 (0.54-1.41)

OR=odds ratio, CI=confidence interval; ORs that are significant are **bolded**

*These statements were phrased positively when asked, but have been phrased negatively here, for ease of interpretation of odds ratios across all statements

EXPERIENCES OF HIV-RELATED STIGMA (ARTICLES III & IV)

The main aim of the studies in this thesis was not to explore perceptions of stigma among PLHIV, as these have been well-documented within Vietnam and beyond (see Background). However, without probing specifically on this issue, participants in articles III and IV raised numerous accounts of stigma which they had encountered, feared, or felt and these fell into three distinct areas: enacted, anticipated, and internalized stigma. I present them here in order to provide greater context to the other findings, which relate to how participants coped with the stigma that they experienced.

Enacted stigma appeared to be a universal experience of women living with HIV. This was particularly highlighted in contacts with family-in-law, where women were spoken to harshly and ostracized due to their HIV status, but also sometimes in the community and in the healthcare setting.

All PLHIV in articles III and IV anticipated and feared the stigma that could result if their HIV status were to be widely known. Persons living with HIV described fearing the effects of inadvertent disclosure of their HIV status when they took antiretroviral medications at work or in public places.

“None of us could take ARV medications in public. Other people would avoid you if they became aware that you got the disease while you try to conceal it. It would be terrible if suddenly people recognize who I am.” Male, 32 years, 6 months on ART

Participants in both the female and male focus groups also anticipated fears of stigma or discrimination towards their family members if others found out about their HIV status. Many individuals countered this through secrecy, seeking to protect their families from the shame of their status being widely known in the community. Some of the family members described fearing stigma if someone were to know that their family member was HIV-positive.

There were numerous descriptions of internalized stigma across many of the interviews with women living with HIV. Women described physically removing themselves from daily family interactions, such as shared meals and shared sleeping arrangements, in order to protect and not negatively influence persons within their families. Internalized stigma was described more often and in more detail by women in the in-depth interviews in article III than among the participants in the focus group discussions in article IV.

RESPONDING TO HIV-RELATED STIGMA (ARTICLES III & IV)

Sources of Support in Living with HIV

In articles III and IV, persons living with HIV described several sources from which they obtained support in living with HIV. These varied greatly depending on the person and also based on whether and to whom the individual living with HIV had disclosed his or her HIV status. The main sources, however, were family and peer support, including organizations for persons living with HIV.

Family

For most persons living with HIV, support from one or more members of the immediate family or family-in-law appeared to be crucial in terms of successful coping with the difficulties of the disease. This support was sometimes described as concrete financial support or support to comply with medical treatment. When beginning treatment for HIV, most patients described that they had to rely on reminders from relatives in order to remember to take their antiretroviral medications as directed. However, over time the role of the family member in providing reminders became less central.

The central function of family as a source of psychosocial support was evident, as was how support and sympathy within the family could help women in article III cope with the stigma they perceived from the community.

The family is a pillar. If they sympathize with me, people outside are not so important. Because people in the family live with me the whole day, every day, and people outside have only short meetings with me. Importantly, if people in the family don't sympathize with me, that is a big sadness for me. Female, 30 years, rural-urban migrant

Generally, it seemed that women who described receiving more emotional or financial support from their own or their husbands' families described less HIV-related stigma. Most, but not all women received family support, with this being a particular issue in relation to family-in-laws. At least two women had been sent away from their husbands' families' homes and others described fears of being sent away if they did not fulfill family responsibilities.

Peer support

Many persons living with HIV described how membership in organizations for PLHIV assisted them in coping with their illness and in minimizing various aspects of stigma. In some cases, this took the form of support during the disclosure of one's HIV status to family members or in assisting in educating family members about HIV to reduce stigma-enhancing practices in the home setting. Organizations for PLHIV were also described as facilitating access to medicines for HIV. In addition, some women said they received better treatment from health workers due to their association with an organization for PLHIV. Lastly, organizations for PLHIV were described by several women as helping them withstand external sources of stigma:

Once I went....to take an x-ray of my lungs. When I was called to come into the room....they looked at me with 'different eyes' (con mat khac). I felt so much self-pity and hurt inside. If I had not been to this club [for PLHIV] I would not stop crying....I just stood there and prayed to release the sadness and pity in my heart and asked God to forgive those people. Then I felt calmer. Female, 26 years, urban-rural resident

Additional support

Participants in article IV verbalised the need for additional support in living with HIV and adhering to ART. Women more often focused on psychosocial support and, while both men and women living with HIV welcomed informational and psychosocial support from health staff, family, and friends, many agreed that their adherence to ART would best be supported by a community-based supporter "*in the same situation*" who was experienced in taking ART. Participants felt that such a peer supporter would more easily show sympathy and assist them in talking to relatives or health care providers if needed. A male focus group participant explained:

"A patient would know how to take the medicine...as he himself has been through this. They can sympathize with you. After all we suffer from the same disease. We have lots of things in common and can easily strike up a conversation. A person without HIV would be difficult to share your problems with because he wouldn't understand you." Male, 37 years, 7 months on ART

Participants suggested that support could be given by PLHIV who were selected by peers and given appropriate training. About half of the female participants stated that they could more easily share their problems and concerns with other women living with HIV.

Enacting culturally prescribed patterns of female behavior: Innocence and protection (Article III)

Women appeared to enact culturally prescribed patterns of female behavior, emphasizing virtue and focusing on fulfilling familial responsibilities to protect and care for others. These behavior patterns often seemed to enable women to more easily access social support and to successfully cope with HIV-related stigma.

In article III almost all of the women interviewed spontaneously explained that they were infected with HIV through their male partners' "indulging" (*choi boi*), a term they used to refer to drug use or visits to sex workers. One exception to this was a woman who described being infected by accidentally sticking herself with a needle while caring for her HIV-positive brother. The women seemed to find comfort in describing themselves as without fault in the HIV infection process. This was viewed as a quality that should alleviate HIV-related stigma, as exemplified by this woman's description of her response to a health worker's comment to another patient in an HIV clinic:

Another patient had side effects from ARVs [antiretroviral medication], and she went to the hospital and a staff member said 'It would have been better for her to die, being alive she can make the family miserable'. I heard this because I was standing a bit behind her. I had a sharp-tongue and said to [the staff member], 'We were not indulging, unfortunately, our husbands transmitted to us. We did not want to be like that [HIV infected]. You are a nurse, how can you say that?'
26 year old, peri-urban resident

Women described several ways in which they reasoned around and acted out what they viewed as their responsibility to protect others. For example, while readily verbalizing that HIV could not be transmitted through casual household contact, women described self-imposing isolation and going to great lengths to be careful so as not to infect others.

I always want to protect other persons. Even when I go to work. I don't want to work in a family with children [for fear of spreading HIV to them]...Even when I come to my family, my parents' house, when I finish the milk, I use boiled water for my bowl, twice. I always think to protect other persons. I am afraid that because of me that I'll make them miserable. Female, 30 years, rural-urban migrant

This was described as a wish to actively protect, not harm, and avoid "influencing". Several women described that this focus on protection led other family members to recognize the woman's commitment to caring for her family which, in turn, meant they were more accepting towards them.

This notion of protection also extended to women's decisions about childbearing, where the pressures of both wanting to have children and of childbearing as a means to fulfil responsibilities to their husbands' families were described. This was particularly important in cases where the male partner was an only son and, therefore, responsible for extending the family line with a male child. The birth of an HIV-negative child was described as having the potential to bring great happiness to both the couple and the family-in-law, and those women who had HIV-negative children seemed to find this a source of great solace, family support and societal acceptance. However, several women also voiced concerns that if they were to have children, the children would grow up without their parents' care and would become "bad persons". These women described plans to forgo childbearing in order to guard against this potentially negative consequence.

Yet another facet of protection and responsibility extended to women's thinking about and planning for their expected time of death, instructing family members not to spend great amounts of family resources on their care when they became sick, but rather to let them die. Several women mentioned this, and seemed to convey such feelings to emphasize their level of care and concern for their family over themselves.

STIGMA AND THE RISK OF LESS EFFECTIVE HIV PREVENTION AND TREATMENT

Information needs and uncertainty (Articles I, II & III)

Despite most community respondents having heard about HIV from one or more sources, some women (34%) and men (42%) reported not having enough information to protect themselves from contracting HIV (significant difference between men and women, $p < 0.001$). More than one-third of all respondents reported not knowing whom they could ask about HIV.

We found evidence of knowledge about HIV transmission that co-existed with uncertainty among women living with HIV. Several women in article III spontaneously verbalized correct understanding of how HIV could be transmitted and then, a few minutes later, directly contradicted themselves by bringing up a worry or question related to an incorrect method of HIV transmission such as through sharing clothes, mosquito bites, or sharing household items. Several women in the same study also verbalized the belief that HIV infection risk should end when the associated risk behavior (in this case injecting drug use by a male partner) had ended. While they knew that HIV could be transmitted via sexual intercourse or shared injecting equipment, they had not realized that HIV could remain, unsymptomatic, even after their partner stopped injecting drugs.

Risk perception (Articles I & III)

Ten percent of women and 14% of men reported feeling at personal risk for HIV ($p = 0.002$). There was an inverse relationship between the expression of stigma towards PLHIV and perception of one's own risk for HIV, with those persons expressing more stigma (i.e., members of the highly stigmatizing and ambivalent class groups) significantly less likely to report feeling at personal risk of contracting HIV.

In article III, we identified some women's lack of awareness about HIV risk, and inability to communicate with new sexual partners about their HIV status. Most of the women described that prior to their HIV diagnosis they had no idea that they or their husbands were at risk for HIV, either because they did not know about the male partners' risk behavior or because they intentionally ignored it. Most women described there being no direct communication with their sexual partners regarding HIV risk or risk behavior. Communication about HIV risk appeared to be linked to societal expectations that the male in the relationship should lead communication between the couple. Women in new sexual relationships at the time of the interviews were widowed or separated; they described longing for new relationships and, understandably, not wanting to be identified with a highly stigmatized disease. Therefore, they did not disclose their HIV status to their new sexual partners.

Yes, I have sex with another. He is well and does not know my status and later on he will know.... No, I told him to use them [condoms] but he does not use them. He just used them 2-3 times. 41 year old, urban resident

Despite recognizing the seriousness of this, one woman described it as impossible to directly tell her new male partner about her HIV status at that point, as she feared rejection as a “*bad person*”.

Disclosure of HIV Status (Articles III & IV)

As expected and reported elsewhere, we found that many PLHIV opted not to disclose their HIV status to others in an attempt to guard against the stigma that they anticipated should their HIV status be known. Most participants in both articles III and IV reported not telling neighbors, work colleagues, or distant family members in rural areas about their HIV status. Many participants had not disclosed their status to every member of their immediate household, particularly to older female relatives and/or their children.

All married female participants in article III had disclosed their HIV status, either directly or as a result of health workers disclosing without permission, to their husbands. Several women also described initially having their own HIV status hidden from them when they tested positive for HIV during pregnancy. The positive HIV test results were told to their male partners and sometimes to their parents-in-law but not to the woman herself until sometime after delivery. Women in article III described male partners not disclosing their HIV status to their wives upon initial diagnosis, in some cases disclosing only when very sick and near death.

Stigma and adherence to ART (Article IV)

The main finding in article IV was that PLHIV’s views on ART adherence and optimal care delivery are influenced by their experiences of HIV-related stigma (see Appendix IV for study themes, categories, and codes). Most participants feared that taking their medication might inadvertently reveal their HIV status to family members, friends, neighbors, or co-workers and this was described as the main barrier to ART adherence.

“I’m very reluctant to take out the drugs. It is not that I forget, it’s just that I don’t want other people to know. At times, I feel alienated. When you go out into the community or even with your relatives you feel ill at ease.” Female, 28 years, 5 months on ART

Concern with HIV-associated stigma was especially emphasized by those living and working in crowded conditions, such as markets, boats, offices, or coal mines, making it difficult to ensure privacy at dose-taking times. To counter this, participants described taking their medications in a hidden manner in order to prevent unwanted disclosure of their HIV status to others. When at work, a majority of participants described trying to avoid suspicion by concealing or disguising their ART medication. Others lied about the type of medication that they were taking or delayed taking the medication until they could do so privately.

SOCIETAL INFLUENCES AND STRUCTURES

Social Evils (Articles I, II & III)

There was widespread support for the policy of mandatory detention in the “05/06” re-education centers, with 93% of adults stating that they believed that these centers helped to stop HIV in the community. Those persons who supported the policy of re-education centers endorsed significantly more stigma statements towards PLHIV than did those who did not support the re-education center policy (mean 4.4 ± 2.0 vs. 2.7 ± 2.4 , $p < 0.001$).

Other factors linked to the socio-cultural context in which these studies are situated relate to the rhetoric of social evils and how it influenced HIV risk perception. This surfaced as an important issue affecting HIV and stigma in the Vietnamese context, and was supported by descriptions of women living with HIV who attempted to put forth an innocent picture of themselves in relation to how they became HIV infected. Many women described outright that they, or their HIV-infected male partners, were not “social evils” and inferred or said outright that many persons who were HIV-infected had gotten it through “indulgent behaviour” or through “social evils”.

In study A, when asked how to prevent HIV, 16% of women and 19% of men ($p = 0.07$) spontaneously listed “avoiding social evils” as an HIV prevention method. Those who saw social evils avoidance as a specific HIV prevention method were significantly more likely to endorse 5 of the 8 stigma statements.

Stigma and the health care system (Articles III & IV)

In article IV we found that the PLHIV who we interviewed did not want home-based directly observed antiretroviral therapy and that PLHIV were positive about the prospect of providing psychosocial and adherence support to other PLHIV. When asked, nearly all participants voiced strong reluctance to the idea of having ART medications delivered to their homes, fearing that home visits by health workers to deliver ART would lead to the unwanted disclosure of their HIV status and result in community stigma against them and their family members.

When stigma was feared in the health care setting, some strategies were described to help counter or prevent it. One respondent (article III) found that the stigma she perceived in the health care setting could be lessened through extra payments to health care staff and viewed this as a positive thing through which she could gain power or influence. Other women attended appointments accompanied by family or PLHIV organization members and thought that this might lead them to be treated better by health care workers.

DISCUSSION

Before going into a discussion of the findings and the meaning that they might have in relation to other research and in relation to each other, I would like to highlight some issues which relate to how the data were collected and the strengths and limitations of the approaches used.

METHODOLOGICAL CONSIDERATIONS

Considerations affecting internal validity (Articles I & II)

It is important to acknowledge possible sources of bias or internal validity which may have affected the findings from study A, as well as what was done to guard against, or minimize this bias (Gordis, 2000). Here I discuss what I see as the strengths and weaknesses of the study design, sampling, data collection, and analysis.

Strengths and Limitations

The strength of study A is that it involves a large population-based sample of adults who were surveyed by well-trained and experienced interviewers within the framework of Filabavi demographic surveillance site. Filabavi DSS has a well-established system for quality assurance monitoring, with 5% of the surveys re-interviewed by a medically-trained field supervisor.

As is quite typical within Filabavi DSS, we had a high response rate to this survey, with only 2 persons not agreeing to participate. We also conducted the survey just before and at the beginning of the rice harvest, so people who were temporarily living away from the district for work were usually back at home assisting their families during the time of our data collection, which corresponded with the harvest.

We constructed multivariate models and carefully checked for interaction between variables that were, in some cases, related (such as sex, migration history, and knowing someone with HIV). I believe that this may have minimized error due to confounding within the analyses for articles I and II.

Something to be aware of when interpreting the results for articles I and II is that the survey on which those articles are based was carried out by a group of all-female interviewers who work as surveyors within the DSS. An all-female interviewer team has been conducting surveys in Filabavi DSS since 1999 and, while they are well-trained and professional full-time interviewers, this could have introduced differential bias if women and men responded to the survey differently based on the sex of the interviewer.

Also, it was not possible to draw a random sample at the level of individual sampling from the selected clusters due to time constraints for the surveyors. To counter this, we created six strata for gender and age from which the individual selected per household was to be drawn, and the

surveyors cycled systematically through the strata in order to select individuals. Without stratified sampling we may have under-sampled younger males, who are less likely to be found at home. Since the survey was conducted at the beginning of the rice harvest, many persons had migrated back to the district to work, but, still, temporary migrants who remained out of the district were unlikely to have been included in our sample.

We attempted to guard against social acceptability bias in the response to the questionnaire by conducting these household surveys in a private area of the interviewee's choosing which was out of earshot of other persons. Interviewers were trained on how to conduct surveys on sensitive topics previously and re-trained for this specific study. Interviewers stated that community members did not seem hesitant in answering the questions and, while it does not exclude the presence of social acceptability bias, we were surprised at the views expressed, particularly those which expressed stigma against PLHIV.

It is possible that some people were tested for HIV and forgot, thus introducing a recall bias that underestimated the HIV testing prevalence. However, testing for a more stigmatized and less common disease like HIV is likely to be remembered. Also, we did not ask about whether HIV test results were received or whether testing was voluntary or not. It has been found elsewhere that voluntary testing and receipt of HIV test results are important determinants to HIV preventative behaviors (Thanh et al., 2008) and accessing care for HIV (Dinh, Detels, & Nguyen, 2005).

The last limitation that I would like to highlight within this sub-study was the measurement around the concept of stigma towards PLHIV. Initially the intention of the sub-study was not to measure stigma within the community and so we didn't include a validated stigma scale in the structured questionnaire. We included items from validated scales that we determined relevant and which worked during pilot testing within the DSS population. Not including a validated stigma scale limited our possibilities for analysis, however, not to be able to measure stigma as a single concept through the use of a stigma score. Within the thesis and in article I, we do not present the results as a scale, rather, we use them together to perform latent class analysis or as individual statements for bivariate analysis.

Overall, I see the lack of the use of a validated stigma scale, coupled with the possibility for a gender-based interviewer bias, as the biggest threats to the validity of my findings and I have tried to take these factors into account in discussing them.

Considerations affecting trustworthiness (Articles III & IV)

Within qualitative research and inquiry, several criteria have been set up to determine the rigor with which the research process was performed. I have chosen to use the criteria proposed by Lincoln and Guba (1985) who put forth the concept of trustworthiness to judge rigor and validity of qualitative studies with a focus on *transferability* (How applicable are our results to other contexts?); *dependability* (Is our research possible to repeat?); and *confirmability* (To what extent are our findings affected by personal interests and biases?) and *credibility* (Have we measured what we set out to measure?) (Dahlgren et al., 2004; Lincoln & Guba, 1985; Sandelowski, 1986).

To judge the transferability of study findings, thick description of the context is necessary so that the reader is more able to judge whether results might be practically or analytically applicable in

other settings. The reader can assess dependability if the researcher is transparent about the analytic decisions made during the course of the study, leaving a written “audit trail” that can be referred to. Confirmability is best assessed through the process of reflexivity, in which the researcher reflects on his or her own role in the study and how it shaped the knowledge generated (Dahlgren et al., 2004; Sandelowski, 1986). In order to judge the credibility of the research conducted in the qualitative studies, it is recommended that the researcher spend time in the setting in which the data is collected as well as with the study material for a prolonged period (this is often referred to as “prolonged engagement”). It is also advised and common to “triangulate” using multiple researchers, methods, and data sources, and that peer-debriefing (either with study participants or experts in the study area) be used to understand and check findings (Dahlgren et al., 2004).

In this section, I reflect on concepts that have influenced trustworthiness in articles III and IV (some of which are relevant to quantitative articles I and II as well) and how I have thought about and tried to handle them.

Reflexivity

Within qualitative research, the researcher and those who are the subjects of research are intertwined and interaction between them is the basis of the qualitative encounter. In qualitative investigation, the researcher is the tool, through whom meaning is assigned and constructed, and, therefore, it is crucial to reflect on and to be aware about the conceptual baggage that one brings to the research experience (Green & Thorogood, 2009). This process of reflection on one’s own role and how it shaped the study process is called “reflexivity” and I describe various related issues here.

Positioning myself within the research

As I touched on in the preface to this thesis, I am a nurse, with a background in public health, and this influences me to see individuals’ health and illness as contextualized in family and social systems, from which health behavior and meaning are ascribed. Several years before starting the research in Vietnam, I worked in clinical nursing and community health in two cities in the United States. Many of the clients and patients who I worked with were injecting drug users and many were HIV-positive. Through that work, I had had the experience of providing both HIV prevention counselling and testing as well as caring for persons in an advanced stage of illness due to their HIV infection. Also, I’ve worked in HIV prevention and HIV-related research in Uganda prior to visiting Vietnam. In the Ugandan setting, official discourse and individual practice encouraged “living positively” and disclosure of one’s HIV status. This was something that I immediately noticed was very different in Vietnam, where HIV seemed to be a much greater source of shame.

I took field notes during the four periods of planning and fieldwork (ranging from 2 weeks to 3 months) that I spent in Vietnam in conjunction with data collection for these studies. In these notes I tried to describe what I did, who I met, and what information I learned. In these descriptions I tried to include as many details as possible. I also used the notes to reflect on my impressions, ideas, and questions in relation to many aspects of life in Vietnam. These notes have helped me understand how my impressions of Vietnam have changed since my first trip there in 2004, and they have informed the reflective process.

This research was my introduction to Vietnam and, although I had worked and lived in other settings that were quite different than my own, I found the Vietnamese context new and unique to anything that I had experienced previously. My initial impressions of Hanoi were that it was an

energetic city with a sense of optimism and I felt, especially during my first visit to Vietnam, that both traffic and people moved quickly, often to my complete bewilderment. As I spent more time in Vietnam and also spent more time with Vietnamese colleagues and friends in Sweden, I began to understand and was aware of many more nuances and emotions, which had initially been hidden from me.

I was treated respectfully and very warmly by most of the people I met in the context of my work in Vietnam. I think that I was viewed as a foreigner and a woman and was not seen as a threat to most of the persons with whom I worked and whom I interviewed. Being a nurse afforded a respect among community members and colleagues and, as is common in Vietnam, people asked my age in order to relate to me as a younger or older person.

Being a woman allowed closer contact with the women who I worked with and interviewed. Also, over the course of my research in Vietnam, I became a mother, spending three months with my first daughter in Vietnam during field work, and noticed that this influenced the way people treated me and provided me with another social role and what I perceived as higher social status among both men and women.

Working collaboratively and in another language

All of the interviews and focus group discussions within this thesis were conducted in Vietnamese, which I do not speak or understand. This was a challenge during the entire research process and I had to rely a great deal on my Vietnamese colleagues to work closely in collaboration to translate the draft research tools, pilot test and revise the tools, train interviewers, and help collect and supervise collection of data, as well as to translate and re-check translation during the qualitative coding and analysis processes. I was very fortunate to work with highly skilled and very patient Vietnamese colleagues during all of my sub-studies, all of whom speak good English and had prior experience with health research through Hanoi Medical University's Health Systems Research Project. Working collaboratively and with translation in many of the steps of the research process required more time than it would have taken had I been conducting the studies more independently, in a language in which I was fluent, but it was also a rich, enjoyable, and thought-provoking experience.

The focus group discussions for study C were conducted by a Vietnamese male co-researcher following a discussion guide that was drafted jointly. I was not present during the FGDs mostly due to logistical reasons rather than as a strategic decision. Another colleague who was present acted as an observer and note-taker and I was fortunate to have verbal and written description of the atmosphere and the content of the discussions. I was present during some of the interviews for study B, and those interviews were conducted using simultaneous translation. However, while it was interesting to observe non-verbal expressions and to be able to influence the course of the interview, it appeared that both my presence as a foreigner and pauses in the interview for translation seemed to affect the natural flow of the interview and appeared to make it more difficult for the respondent to freely share her thoughts. After conducting and carrying out initial analysis on the first three interviews, and confirming that my Vietnamese co-researcher was skilled in the interview process, she fully assumed the role as interviewer for the remainder of the interviews without me being present. This approach seemed to yield richer information from the women interviewed subsequently. Between interviews, my co-researcher and I discussed the interview findings and revised the interview guide and sampling strategy for the next interview.

For both studies B and C, all of the FGDs and interviews were recorded and transcribed. For study C, my co-researcher and I jointly transcribed and translated the first two interviews, with her listening to the Vietnamese recording and verbally translating to English and me typing in English what was said during the interview. This approach was enormously fruitful in terms of discussing the meaning of what was said and understanding Vietnamese concepts and sayings. The joint transcription process also served as a first step of analysis. However this approach took a lot of time (3 days for the first interview) and due to time limitations the remaining interviews were transcribed and translated by my co-researcher and later discussed between us during initial cleaning and coding.

It was extremely helpful that the study interviewers for studies B and C were able to participate in all steps of the research process and coded, analyzed, and co-authored the articles connected to those studies together with me. This enabled us to have many long discussions, both during data collection as well as subsequently during the process of coding and analyzing the study data, about the meaning of various terms and concepts. This resulted in much richer possibilities for understanding the data in context and allowed us to struggle together and challenge each other, each from our own perspectives, as to how to understand and construct meaning from the data. While I was usually the outsider needing clarification of terms and practices from my “insider” Vietnamese colleagues, at times it appeared my questions caused them to reflect on things they had taken for granted which may have had previously unrecognized meaning in the interview situation.

Hierarchy in the interview situation

In both studies B and C, non-HIV positive interviewers interviewed PLHIV and their family members about various aspects of living with HIV. HIV-related stigma is high in the Vietnamese context, as I described in the Background section. It is likely that most persons living with HIV, both in Vietnam and elsewhere, would be eager to portray themselves as “good” people in an interview situation with a person who was not HIV-positive. This dynamic may have been present in the interviews that we conducted and it was something that was difficult to avoid. We considered employing an HIV-positive interviewer, however, we were unable to locate someone who was experienced in interviewing and able to speak English, which were requirements to enable us to carry out the research. For article IV, the interviewer was a medical doctor who cares for PLHIV and who is known for having very good rapport with patients. His presence may have influenced respondents to minimize the extent to which they reported not adhering to medications for HIV; however, we found that they reported more non-adherence than we had expected. For article III, we chose to try to minimize hierarchy in the interview situation by using an interviewer who was quite young. She was the same age, if not younger, than most of the respondents and she did not have a health background, although she was familiar with health research and had conducted interviews previously. The interviewer sought to further minimize the hierarchy bias by stressing her familiarity with PLHIV based on many prior meetings with other PLHIV and by taking great care to make the respondent feel comfortable. Finally, we took the possibility of hierarchy in the interview situation into account in the analysis for article IV as, perhaps, representing the manner in which an HIV-positive person would portray themselves to someone who is not living with HIV.

Triangulation

Triangulation usually refers to employing multiple methods to examine a single problem, often through the combination of qualitative and quantitative approaches. In addition to *methods triangulation*, *data triangulation* (the use of more than one sources of data in a study), *investigator*

triangulation (the use of several different researchers' perspectives), and *theoretical triangulation* (the use of more than one theoretical perspective to interpret data) can be used (Patton, 2002). Both articles III and IV used methods, investigator, and theoretical triangulation. Overall, the thesis uses data triangulation with different types of data from different studies used to look at the picture as a whole.

Credibility

During analysis for both articles III and IV, the codes and the relationships between them were organized under a central theme. Preliminary findings were repeatedly discussed among the research team and compared against the individual interview cases to ensure that our interpretive analysis remained relevant to the individual cases. In article III, theoretical concepts and interpretation were then discussed with two Vietnamese medical practitioners working with HIV patients to receive outside feedback and validation of our interpretive findings.

DISCUSSION OF FINDINGS

Cultural influences: Gender and Social evils

There were factors identified in all of the articles in this thesis that relate to or are explained by larger individual and family characteristics and levels of knowledge, and community factors, including healthcare system factors, as well as wider socio-cultural influences. First, I will discuss two such factors which came through in several of the studies in this thesis: gender and the concept of social evils.

Gender

Gender was a dominant factor in all of the studies in this thesis and appears to affect both the creation and expression of stigma toward persons living with HIV as well as the outcomes of HIV-related stigma for both PLHIV and those who were not living with HIV. We found that women adhered to gendered patterns of behavior in order to underscore their virtue and this served to secure their position within the family and, thereby, in society. These patterns of behaviour seemed to be culturally sanctioned and can be traced back to Confucian principles that dictate expected norms of female behaviour (Binh, 2004; Go et al., 2002). Women described both fulfilling responsibilities to protect others and being protected by others, and this had implications for disclosure, social support, the ability to access timely HIV care, adherence, and the ability to guard against HIV-related stigma.

These guiding principles of virtue and protection of others point to the very limited power spheres that are available to many married Vietnamese women, where disclosure of her own or her sexual partner's HIV status is often kept from her. This lies in contrast to other settings where women, even in positions of submission or social vulnerability, are described as able to control the course of their disclosure (Sandelowski et al., 2004). It has also been documented in Vietnam previously and in this thesis that women are not always in control of the disclosure process, with health workers or authorities sometimes disclosing to family members on their behalf (Oosterhoff, Hardon, Nguyen, Pham, & Wright, 2008). In contrast, Lekganyane (2011) describes women in South Africa in a context of high HIV-related stigma, but who appear to be fully in control of the process of their own disclosure (Lekganyane et al., 2011). The non-confidential process of disclosure has been

shown to have negative social, economic, and health consequences for women living with HIV in Vietnam (Oosterhoff, Hardon et al., 2008).

This is not the first time that Vietnamese women's special responsibility to uphold moral virtue and to protect others has been described (Gammeltoft, 1999; Rydstrom, 2006; Vijayarasa, 2010), but this is the first examination of these issues in relation to women living with HIV. Many women living with HIV described their infection being the result of their male partners' current or former drug use or visits to sex workers. These women described being unaware of or unable to communicate about their male partners' HIV risk, and often did not seek testing until their male partner had died or until they were tested positive by chance during pregnancy. Despite the profile of many of the women in our study being "low-risk" prior to their diagnosis and a growing proportion of HIV infections in Vietnam among this low-risk group of women, we did not find wide provision or uptake of HIV testing in pregnancy in our study sample.

Despite our interpretation of the limited power available to the women in our studies, we did see them using the power available to them in an agentic way, to actively safeguard their sometime vulnerable and precarious position, within the family and society. Ha (2008) also describes how married Vietnamese women use their "silence" in order to negotiate their sexual lives, while ensuring happiness and harmony within the family (Ha, 2008).

One further example of this agency is the protection that women described in decisions about childbearing. Women balanced the needs of the family-in-law and their own wishes for children with the negative future that their potential child might have and usually opted against childbearing. In a study of HIV-positive women in Northern Vietnam, Chi and colleagues (2010) found the same reproductive dilemmas and described the pregnancy termination being mainly a result of the fear of not being able to provide care to the child (Chi, Hanh, Rasch, & Gammeltoft, 2010). The situation of deferred childbearing among women living with HIV in Vietnam lies in contrast to that of most sub-Saharan African settings, where HIV is often not seen as a reason not to have children. Although the fertility rate is higher generally in sub-Saharan Africa and access to abortion legally available in Vietnam, the reasoning behind these decisions appear to differ between the contexts (Beyeza-Kashesya et al., 2010; King et al., 2009).

Finally, it is also important to consider that women were examined more closely in this thesis through study III and that there is not an equivalent close examination of men living with HIV within this thesis. Salter et al (2011) report on coping among male IDUs in Northern Vietnam and have similar findings in relation to men's isolation of themselves from shared family spaces, as well as in their concern for how the HIV infection would affect the family unit (Salter et al., 2011). Men discuss their self-isolation as well as concerns for the economic well-being of the family in terms of protection. However, in contrast to the women in article IV, men described contemplating suicide to prevent secondary stigma to the family and do not describe the same fears of rejection and expulsion from the family unit that were described by women in article IV (Salter et al., 2011). Women described many instances of finding themselves in vulnerable positions in which they experienced or feared being sent away from their husbands' families' homes. In contrast, another qualitative study with male injecting drug users in Thai Nguyen, Vietnam found that after disclosing their HIV status to their family members, most men felt more support and acceptance from their families than before (Rudolph et al., 2011).

Social evils

In both articles III and IV, much of the fear of disclosure of one's HIV status was associated with trying to protect one's family from the negative societal view of being closely associated with social evils. Women actively situated themselves on the "innocent" end of the HIV-infection continuum in order to avoid the stigma associated with drug use and sex work. The "innocence-to-guilt continuum" described by Ogden and Nyblade (2005) explains the manner in which drug users and sex workers are considered more "guilty" by society for their HIV infection, while women infected with HIV through their husbands, children infected in utero, and health workers infected through accidents are all considered to belong to the innocent end of the continuum (Ogden & Nyblade, 2005). This is sometimes referred to as "layered stigma" and it appeared that the women in our study actively sought to de-link the layers in relation to their own identities, making statements which indicated blame toward their husbands who were injecting drug users or toward other persons living with HIV who had been "indulging" (Chan et al., 2007). While this layering of stigma certainly exists in generalized epidemic settings, it appears less frequent since HIV is not entirely or mostly concentrated in particular socially stigmatized groups.

The existence of mandatory re-education centers that detain IDU and CSW who are apprehended for a period of two to five years is somewhat unique to Vietnam, although similar programs do exist in China (Hammett et al., 2008). There are, of course, very negative societal associations attributed to high risk groups such as IDU, CSW, and men who have sex with men in many countries in the world (Ogden & Nyblade, 2005). However, in Vietnam, the effect of the social evils rhetoric of the past two decades has been particularly negative and this has been linked, both in this thesis and elsewhere, to enhanced HIV-related stigma (Brickley et al., 2008; Hammett et al., 2008; Rydstrom, 2006; Thanh, Moland, & Fylkesnes, 2009; Thi et al., 2008; Vijayarasa, 2010). The use of the term social evils, not only among the population, but actually introduced in government policy and institutionalized in government agencies such as the Department of Social Evils Prevention (DSEP) within the Ministry of Labor, Invalids and Social Affairs, continues to reinforce and legitimize this approach.

We found very high agreement among men and women in the population for sub-study A in support of mandatory re-education 05/06 centers as a method to prevent HIV in the community. Not surprisingly, those who expressed support for the re-education centers endorsed significantly more stigmatizing statements towards PLHIV. Studies in India and elsewhere have found very high support for coercive policies towards persons living with HIV, such as mandatory testing and refusal of access to education or health care (Ekstrand, Bharat, Ramakrishna, & Heylen, 2011). Recently there has been increased critique of the mandatory re-education policy, mostly driven by donors to Vietnam, and recognition of their high cost and very high rates of recidivism (Nguyen Ha et al., 2010; Turnbull, 2006). Additional critique has referred to the centers as "incubators of the epidemic", with an estimated 40 to 50% HIV prevalence among residents in some of the centers, limited treatment and care, and known HIV transmission occurring within the centers (Turnbull, 2006). The critique of the 05/06 centers has been based on a human rights approach and a recognition of both drug use and sex work as societal structural problems, with sex work an effect of limited opportunities and oppression of very poor women and injecting drug use a medical problem in need of treatment and prevention including opioid substitution treatment and needle and syringe programs (Hammett et al., 2008). Mandatory internment and the linking both in policy and practice of HIV risk to social evils have obvious implications for the enactment of HIV-related stigma against persons living with HIV (PLHA) and for the uptake of HIV prevention and

risk messages for all members of Vietnamese society (Hammett et al., 2008; Hong et al., 2004).

While Vietnam has made significant movement toward a more rights-based approach to HIV prevention and care in recent years, data from our study population shows that there remains widespread support for the policy of mandatory re-education through 05/06 centers, despite them having existed only since 1996 (Hammett et al., 2008; Nguyen Ha et al., 2010). This popular community support will likely be a barrier to an approach that seeks to medicalize the treatment of drug use and sees both drug use and sex work as problems stemming from wider societal structural issues. It is likely that anti-stigma campaigns in Vietnamese communities would need to influence and harness popular support in order to re-frame drug use as a medical problem and both sex work and drug use as tied to societal structural problems, rather than as criminalized “social evils” as has been the main approach during the past decade (Maher, Coupland, & Musson, 2007).

Patterns of stigma towards PLHIV

In article I we found high and somewhat complex patterns of stigma towards PLHIV among both male and female community members of all ages in a rural setting. The stigma expressed towards PLHIV by respondents was similar to that found in a study conducted in 2005 in Southern Vietnam (A. T. Nguyen et al., 2008) and appeared higher than that found in a national study conducted in 2005 in Vietnam and a study of Chinese urban migrants both of which used slightly different questions (General Statistics Office Vietnam, National Institute of Hygiene and Epidemiology Vietnam, & ORC Macro, 2006; Liu et al., 2005). In article II, 64% of adults endorsed the statement that PLHIV should feel ashamed, similar to the rural sample in the 2005 study by Anh Tuan Nguyen et al while the urban sample from the same study reported lower stigma (45%) (A. T. Nguyen et al., 2008). When compared with countries with more advanced HIV epidemics and much higher HIV prevalence, the Vietnamese in our studies expressed much more stigmatizing attitudes towards persons living with HIV. Reports on the same measure from non-Vietnamese settings are much lower ranging from 8-34% in various South African locations (Kalichman et al., 2005). In Botswana, fewer people (27%) would be reluctant to share a meal with a PLHIV (Wolfe et al., 2008) as compared to 44% in our sample.

While it is difficult to compare stigma attitudes across contexts and time due to the lack of systematic tools and sampling methods for measurement, it does appear that settings with concentrated HIV epidemics, such as Thailand, Vietnam, and India, have recorded higher stigma than that reported in settings with generalized HIV epidemics (Ekstrand et al., 2011; Genberg et al., 2009). There is some evidence that the availability of antiretroviral therapy to treat HIV is associated with less stigma towards PLHIV (Campbell et al., 2010; Genberg et al., 2009; Wolfe et al., 2008), however conflicting results have also been reported (Agnarson et al., 2010). The “ART effect” is a possible explanation for why we found higher endorsement of stigma toward PLHIV in this rural area than was reported in the 2005 studies in urban Vietnam where ART became available in 2004 (in Bavi district ART was still unavailable when data were collected in 2007).

Results from article I highlight that persons who reported knowing someone with HIV were more likely to belong to the least stigmatizing group. This could help explain why stigma is often found to be higher in countries with concentrated HIV epidemics where, by definition, fewer persons are infected with HIV and the likelihood of knowing someone with HIV is lower for any given individual. Following this logic that people less exposed to PLHIV have more stigmatizing attitudes

toward them, stigma in the rural area of our studies was higher than in urban settings in Vietnam, a finding similar to that of studies in South Africa and in Botswana (Kalichman et al., 2005; A. T. Nguyen et al., 2008; Wolfe et al., 2008). This is likely also the explanation for why persons with a history of migration out of the district had significantly lower odds of high stigma group membership, since migration occurred most often to urban areas for work. It is likely that those who have not migrated outside of rural areas in our study sample also had less likelihood of being exposed to HIV information and stigma reduction campaigns that target urban areas.

In addition to finding less stigmatizing attitudes among those who reported knowing someone with HIV and among those who had migrated, we found that women and those with less formal education were more likely to report the most stigmatizing attitudes. The inverse relationship between years of education and level of HIV-related stigma has also been reported in South Africa, Botswana, China, and previously in Vietnam (General Statistics Office Vietnam et al., 2006; Kalichman et al., 2005; Liu et al., 2005; Wolfe et al., 2008). Other studies have not found the relationship between higher stigma and female gender that we found in this study and this is an issue for further investigation (General Statistics Office Vietnam et al., 2006; Liu et al., 2005; A. T. Nguyen et al., 2008; Wolfe et al., 2008). It is possible that our findings were influenced by the all-female group of interviewers differentially affecting how women and men answered the questions. It seems most likely, in that case, that stigma among men would have been under-estimated due to a social acceptability bias.

There was a conflicting relationship between hearing about HIV from more sources and stigma group membership. Hearing from more sources was both a factor making it more likely to be in the least stigmatizing group (as compared to highest stigmatizing) and also to be in the ambivalent group (as compared to least stigmatizing). This finding appears to contradict itself at first glance and led me to further analysis to try to understand which information sources were most associated with endorsing stigmatizing statements. It was not possible, with the data collected for this thesis via a quantitative survey tool, to clarify the relationship definitively and this is likely both due to the varying quality and conflicting messages on HIV via information provided by both public health authorities combined with sensationalized media reports of HIV infection and transmission (Ogden & Nyblade, 2005). A clear predictive relationship between media messaging and HIV stigma has been inconclusive in studies conducted outside of Vietnam (Hutchinson, Mahlalela, & Yukich, 2007); however, more focus on the nature of HIV informational messaging might help to clarify the type and means of messages that best reduce stigma against persons living with HIV while providing correct HIV prevention information.

Lastly, we found it interesting that almost 20% of the population in our study sample were highly unsure or ambivalent in their attitudes towards PLHIV. For many of the stigma statements these persons were likely to say, "I'm not sure" or "maybe". Some of these persons stated that they could not definitively answer a specific question unless given more information such as, for example, how the person had been infected with HIV was given. This ambivalence and tendency to qualify one's answer based on how the PLHIV became infected with HIV would appear to support the "innocence-to-guilt continuum" (Ogden & Nyblade, 2005). However, since they didn't express outright negative views in all cases towards PLHIV, it is also possible that persons in the ambivalent group have the potential to be influenced towards more accepting attitudes with targeted and high-quality anti-stigma messaging.

HIV testing

HIV testing is both a preventative and screening tool that allows entry into care for those who are HIV-positive, and risk-reduction counselling for those who tested both negative or positive. In order to seek or accept testing, one normally acknowledges the possibility of being at-risk for HIV. Article II found that less than 8% of the adult population had ever tested for HIV in this rural area, and women who had been pregnant in the three years prior to the survey had no increased likelihood of having tested for HIV. Previous reports from Vietnam indicate much higher testing rates in urban Vietnam, where 25% of adults and 60% of pregnant women reported having tested for HIV (General Statistics Office Vietnam et al., 2006; A. T. Nguyen et al., 2008). In neighboring Thailand, where the HIV epidemic started earlier and has received more public health focus, 48% of adults were found to have tested for HIV (Chamrathirithon, Kittisuksathit, Podhisidha, Isarabhakdi, & Sabaiying, 2007).

In article II a variable for stigma towards PLHIV was not included in the multivariate model since measuring stigma as a uniform concept was judged difficult because we had not used a validated stigma scale. However, in univariate analysis conducted and presented within this thesis, we see a clear relationship between the endorsement of stigmatizing statements towards PLHIV and not having tested for HIV. The inverse relationship between HIV testing and HIV-related stigma has been documented in diverse populations in Brazil, South Africa, Thailand, and Uganda (Bwambale et al., 2008; Genberg et al., 2009; Kalichman & Simbayi, 2003; Pulerwitz et al., 2008). So, while the negative relationship between stigma and HIV testing appears fairly strong both in our settings and elsewhere, all of the studies have been cross-sectional, making it difficult to establish causation. Indeed, the experience of HIV testing could provide education and information to those who undergo testing, leading those persons who have tested to feel and express less stigma towards PLHIV.

To try to understand why HIV testing rates are low, in article II we examine the various factors which are associated with less testing in our population and find that economic status and residence in a remote location are the factors which point to the need for health care service attention to more equitable delivery of HIV testing services. Geographic access barriers to HIV testing provision are well-documented (Makwiza et al., 2009; Schur et al., 2002) and important to take into account since more than 70% of Vietnam's population live in rural areas, making attention to these regions of essence for HIV prevention and control (World Health Organisation, 2008). In the study area, HIV testing cost about 30,000 Vietnam Dong (about \$ 1.80 US) at the time of data collection and was paid for out-of-pocket. While the amount may seem negligible, we saw a strong relationship between higher economic status and past HIV testing, as has been documented in other parts of Vietnam and in Malawi (General Statistics Office Vietnam et al., 2006; Helleringer, Kohler, Frimpong, & Mkandawire, 2009). There is no evidence from Vietnam that HIV infection is associated with higher economic status, as has been suggested in some settings with generalized HIV epidemics (Piot, Greener, & Russell, 2007).

An additional issue identified in article II was the apparent lack of any increased testing amongst the population of women who had recently been pregnant, indicating that the program to prevent mother-to-child transmission (PMTCT) of HIV had not reached this area by 2007, despite national plans stating that this service should have been offered. In contrast, in a more urban setting in Northern Vietnam, over 90% of pregnant women had a least one HIV test during pregnancy

in 2007 (Hanh, Gammeltoft, & Rasch, 2011) while in generalized HIV epidemics settings like Uganda, testing rates of over 50% are reported during pregnancy (Larsson et al., 2009).

Even in concentrated HIV epidemic settings with low resources, PMTCT programs have been found to be cost-effective and are one of the few ways that HIV can be prevented with high certainty if the necessary components of PMTCT are delivered (Johri & Ako-Arrey, 2011). In addition to providing testing during pregnancy to be able to prevent HIV transmission to the child in utero, testing during pregnancy can identify women who are in need of antiretroviral therapy to improve their chances of survival. The provision of PMTCT can provide routine HIV testing to women who might otherwise consider themselves “low risk”, due to not knowing or not acknowledging their male partners’ current or past risk behaviours, such as many of the women in article III. “Low risk” women are, indeed, thought to be one of the fastest growing groups for new HIV infections in Vietnam and they are often missed by programs which target the highest risk groups engaged in sex work or drug use (Ministry of Health Vietnam, 2005). Previous research in Vietnam has found that about half of women did not accept it, and that not testing for HIV was associated with not believing that one was at risk (Dinh et al., 2005). Expanding the provision of testing during pregnancy to all areas and providing it routinely in a high-quality manner could normalize the testing and increase the uptake of testing among pregnant women in all areas of Vietnam. This would likely help to increase the case-finding for “low risk” women living with HIV who would not seek testing based on risk perception.

A final issue identified in article II in relation to needs for HIV testing provision, was that more than three-fourths of those who considered themselves at-risk for HIV had not tested for HIV and, overall, very few people had plans to test for HIV in the future. While, as is discussed in article II, the provision of free universal HIV testing in a concentrated HIV epidemic setting is probably not the best use of limited public health resources, it is important that persons who feel at-risk for HIV be targeted for HIV testing. A recent analysis of HIV testing in Vietnam between 2002 and 2007 reports that 19% of voluntary counselling and testing encounters were HIV-positive (Hong et al., 2011). This indicates that testing for HIV is being targeted too infrequently and only to the most high-risk individuals, which likely results in many persons not being screened for HIV. A more appropriate level of HIV testing could be achieved through an enhanced focus on high-quality, confidential, low-cost, provider-initiated HIV screening to targeted populations. In addition to the current focus on the most at-risk populations of injecting drug users, sex workers, clients of sex workers, and men who have sex with men, there could be a more general focus on persons who believe they are at-risk for HIV. We saw evidence in article IV that women who did not expressly describe their male partners’ HIV risk behaviors such as injecting drug use often had difficulty getting providers to agree to offer them HIV testing services. In many settings, including Vietnam, stigma associated with risk behaviors and with HIV is high and it is likely that many individuals who have engaged in such behaviors do not want to openly discuss this with health care providers. More training for health care workers and a focus on routinely provided, high-quality, opt-out HIV testing combined with non-stigmatizing community HIV education, prevention and testing campaigns could help normalize HIV testing in the health care setting (Nyblade, Stangl, Weiss, & Ashburn, 2009).

Outcomes of stigma creation, expression, reception, and perception

Social support

One of the findings from article III was that not all women seemed to internalize the stigma that they experienced to the same extent. Perception of the stigma that women described appeared to be mediated by the support that they received from within the family as well as from organizations for PLHIV.

Support from family was described as central in articles III and IV to helping persons living with HIV manage several practical and emotional aspects of their lives. In article IV, family was described as providing support during the beginning of antiretroviral therapy to take their medications, although this support declined over time as it was deemed, perhaps, less needed. In article III, women who received more family support described less HIV-related stigma. The importance of family support in helping PLHIV is not unique to Vietnam and has been documented in several settings to protect against HIV stigma and discrimination (Maman et al., 2009; Salter et al., 2011). However, this stands in contrast to a study conducted in Vietnam by Hanh et al (Hanh, Rasch, Chi, & Gammeltoft, 2009) which found that pregnant women described health workers as the most important source of support, whereas the role of healthcare was far more limited in our studies III and IV than that of family.

Most of the focus on helping PLHIV to cope has been on the individual-level or on the health care setting. In a setting like Vietnam, where family appears to play a central role, strategies that further incorporate family could enhance efforts to prevent or reduce HIV-related stigma. Salter et al described the importance of family among HIV-positive male IDUs ability to cope with HIV and recommended interventions which reconsider the socio-cultural context of “self” (Salter et al., 2011). This recommendation is underscored by the findings in our article IV with women living with HIV.

Organizations for PLHIV were described as an important source of support in study IV, with women describing that it helped them to disclose their HIV status to family members, to gain access to less stigmatizing HIV care, and to feel less badly when confronted with HIV-related stigma. We have found evidence elsewhere that organizations for PLHIV have been helpful in countering HIV-related stigma and in helping with practical aspects of life with HIV (Liamputtong, Haritavorn, & Kiatying-Angsulee, 2009; Nam et al., 2011; Oosterhoff, Anh, Yen, Wright, & Hardon, 2008). Liamputtong et al describe how women in Thailand use the groups to reconstruct their identities in order to counter the societal image of themselves as bad persons (Liamputtong et al., 2009). In a review of stigma-reduction projects in Southeast Asia, Stangl et al describe that a large barrier to the work of organizations for PLHIV is that persons must publically engage in order to join and benefit from them, and that often self-stigma inhibits PLHIV from doing this (Stangl et al., 2010). It is noteworthy that the literature reporting on organizations for PLHIV from Southeast Asia focuses mostly on women’s involvement in such organisations, although men are also involved in some organizations. Based on results from article IV, we recommend assessing whether acceptance in some of these organizations could be contingent upon acting in accordance with the specified gender or behavioral norms, for example not engaging in drug use or sex work. As has been documented by Oosterhoff et al in the Vietnamese context (Oosterhoff, Anh et al., 2008) some of these organizations have a history of drug-testing their members or not allowing members to use drugs. It is also of note that organizations for PLHIVs’ activities are heavily focused around

projects of community service, including providing community education and serving soup to patients in hospitals. HIV prevention and care in many countries is structured around the existence and services of such civil society organizations which provide care and support to PLHIV; however, in light of results here and in other settings, it is of note that they often rely heavily on women supporting and caring for others (Tarimo, Kohi, Outwater, & Blystad, 2009). Nonetheless, more attention could be paid to the central role of organizations for PLHIV in the Vietnamese context and beyond in helping women, and men as well, to cope with the HIV-related stigma that they experience. Strategies for supporting organizations for PLHIV would likely help to further stigma-prevention efforts and increase access to better quality HIV care.

Finally, respondents in study IV deemed peer support from other PLHIV (not necessarily through an organization for PLHIV) as the ideal source of support for achieving good adherence to ART, and for receiving extra emotional support in living with HIV. Participants in this study appeared to welcome involvement in their own treatment and listed several ways in which PLHIV could provide peer-support for adherence to ART. Considering the limited human resources for health care and increasing numbers of PLHIV (Barnighausen, Bloom, & Humair, 2007), peer-support among PLHIV should be assessed as a strategy to reduce the burden of work and cost of care, improve adherence to ART, strengthen the role of PLHIV, and most importantly, reduce stigma in the community through the empowerment of PLHIV (Altice, Maru, Bruce, Springer, & Friedland, 2007).

Stigma and the risk of less effective HIV prevention and treatment

Social distancing and risk perception

We found a negative relationship between the endorsement of stigmatizing statements towards PLHIV and the belief that one was at-risk for HIV. Within the literature, there is still debate as to whether holding stigmatizing beliefs towards PLHIV is, indeed, associated with engaging in higher HIV risk behavior (Riley & Baah-Odoom, 2010). However, there does seem to be an inverse relationship between risk perception and stigmatizing beliefs towards PLHIV reported in South Africa, China, Ghana, and Namibia (Campbell et al., 2007; Liu et al., 2005; Riley & Baah-Odoom, 2010; Smith & Morrison, 2006). Although most of these studies are cross sectional in nature and, therefore, not explanatory in terms of the causal direction of the relationship, this relationship appears to indicate two potential harms. First, persons who have a lower risk perception, while they may indeed be at lower risk for HIV based on their behaviours, may ignore HIV prevention information and messages which could benefit them or others they know. Second, those who have greater stigma towards persons living with HIV enhance societal stigma and, in the process of expressing that stigma, further distance themselves (and others they influence) from HIV prevention messages which could benefit them.

We found several ways in which stigma appeared to contribute to HIV-related risk in Vietnamese society. We have already discussed how more stigma towards PLHIV was associated with lower odds of believing that one was at-risk for HIV as well as lower odds of HIV testing (articles I and II). While we didn't measure the actual risk-taking and risk behavior of those persons in the community, the widespread lack of acknowledgement of HIV risk appeared to fall in line with descriptions from article IV of women who failed to acknowledge HIV-related risk, even if they suspected that their husbands had used or did use drugs.

Additional risks we identified in article III centered around how women communicated (and did not communicate) about HIV risk. For some women, enacting culturally-expected virtuous behavior appeared to make it more difficult to speak to health workers or new sexual partners about HIV. Some of the women had so completely distanced themselves from the concept of “social evils” through the cultivation of an identity of innocence and virtue, that they were not able to appropriately gauge HIV risk or to access HIV prevention. Until women openly described their husbands’ drug use, they had difficulty in accessing HIV testing services. There were also indications of the incorrect perceptions that have arisen through the “social evils” rhetoric of strongly linking HIV and drug use without providing clear messages about HIV transmission as some women described being surprised that their male partners had tested HIV-positive after they had stopped using drugs. A final risk was identified in women asserting their innocence in becoming HIV-infected, but then appearing to redirect stigma towards those PLHIV who engaged in drug use or sex work. While it is easy to understand the reasons for doing this, it has implications for increasing blame and stigma against other PLHIV and fuels the cycle of stigma against PLHIV on a societal level (Herek & Capitanio, 1999; Mahajan et al., 2008).

Disclosure

Stigma is probably the main factor affecting the voluntary disclosure of one’s HIV status as has been documented in this thesis in articles III and IV and previously within Vietnam (Salter et al., 2011) and in South Africa and Brazil (Gilbert & Walker, 2010; Hutchinson et al., 2007; Pulerwitz et al., 2008). This was also confirmed by a meta-analysis, where the negative relationship between stigma attached to HIV and the disclosure of one’s HIV status was documented in diverse populations, mostly in North American and UK settings (Smith, Rossetto, & Peterson, 2008). In articles III and IV, respondents reported not disclosing their HIV status to persons in the community, co-workers, or distant relatives. Some women living with HIV did not disclose their HIV status to everyone living in their own household for fear of bad treatment or to protect their older female relatives or children. In contrast, Rudolph et al (2011) found that HIV-positive male IDUs in Vietnam described more support and less stigma after disclosing their HIV status to their family members (Rudolph et al., 2011). This could be indicative of the more precarious position of female members of the household, particularly when they are dependent on the family-in-law for financial and social support.

It has been documented previously in Vietnam that those who do not disclose their HIV status are less likely to seek medical care for their HIV, therefore, putting them at increased risk of premature death (Nguyen, Bygbjerg, Mogensen, & Rasch, 2010). One of the major reasons for HIV-positive women not to seek medical care in India was fear of stigma (Kipgen, Yesudian, Marrone, & Stalsby Lundborg, 2011). In light of the increased access to antiretroviral treatment in Vietnam during recent years due to the scale-up of ART provision throughout the country, and new research showing the positive effects of early treatment for both individuals and for prevention, disclosure is crucial, in that it supports treatment uptake (Cohen et al., 2011).

Adherence to ART

There are many factors that influence ART adherence (see Osterberg & Blaschke, 2005 for a thorough discussion of this) and investigating all of these was not the focus of this thesis. Adherence to ART is important so that the person taking the medication maintains a high level of viral suppression and minimizes viral resistance. In article IV, PLHIV in Vietnam who had recently started taking ART described stigma as the main barrier in adhering to ART. This has

been found in adult populations in several settings in qualitative and quantitative studies (Dlamini et al., 2009; Murray et al., 2009; Nachega et al., 2004; Sabin et al., 2008) in diverse settings including China, Lesotho, Zambia, South Africa, Malawi, Swaziland, and Tanzania and contrasts with findings from sub-Saharan African settings where the biggest barriers to adherence are financial (Coetzee, Kagee, & Vermeulen, 2011).

While great focus has been placed on increasing access to ART in low and middle-income settings, it is crucial to keep in mind that these medications will not work in people who do not take them regularly, and that structural and individual-level stigma must be addressed to ensure that ART programs be highly effective, so that adherence to ART remains high. This becomes even more important as guidelines and new research encourage earlier, and thus longer-term, antiretroviral therapy for those infected with HIV, and even pre-exposure prophylaxis for high-risk individuals (Cohen et al., 2011; Grant et al., 2010; WHO, 2010).

HIV Stigma Framework

Finally, I would like to return to the HIV Stigma Framework (Earnshaw & Chaudoir, 2009) to discuss how it relates to this research and how it might be applied in the Vietnamese setting. The HSF allowed me to conceptualize some of the areas covered within this thesis, while identifying some places where the framework did not fit closely with what I observed of the stigma processes and outcomes among my study populations in Vietnam. Here, I briefly suggest some modifications for the use of the HSF in Vietnam in relation to the empirical data presented (see Figure 6, with modified framework depicted).

First, instead of calling the processes “mechanisms”, as the original HSF does, I found it more helpful to use the terms “creation and expression” of stigma and “perception and reception” of stigma to differentiate the mechanisms from each other. This is partly a matter of being more specific in spelling out the mechanisms for the distinct processes, but also relates to the stages of stigma described by Link and Phelan (Link & Phelan, 2001; Yang et al., 2007).

Second, I saw the processes for who creates and who perceives stigma, as more complicated than the dichotomous process of non-PLHIV as stigma creators and PLHIV as stigma receivers. PLHIV can also express HIV-related stigma against other PLHIV (article IV). My research and other research from Vietnam (Salter et al., 2011) have found that family members of PLHIV can experience secondary or vicarious stigma, much along the lines of the PLHIV themselves. To try to acknowledge this I have removed the labels in the framework that indicate that HIV-uninfected are the sole stigma creators and that PLHIV are the sole receivers of stigma. However, it is acknowledged that PLHIV are most often those who experience and perceive HIV-related stigma and that non-PLHIV are most often those who create and express it. However, both PLHIV and non-PLHIV could take part in both mechanisms, even simultaneously.

Given the nature of family relations in Vietnam, as previously described, it was impossible to place the individual in the Vietnamese context apart from family responsibilities and relationships. In the modified version of the HSF, individual and family are placed together, in creating and receiving HIV-related stigma, acknowledging the influence of family in the processes that affect the individual (Yang et al., 2007).

Last, in the Vietnamese context, at least, and probably in every context, I discovered that important cultural and structural factors influence how stigma is enacted and felt by individuals. In research presented in this thesis, the norms of the community are important (articles III and IV), and cultural factors such as gender and the concept of social evils (articles I-IV) and structural factors such as laws and policies play a very important role in determining the extent to which stigma is created, expressed, and perceived. To acknowledge these influences, the HSF is placed in within a behavioural ecological model (Hovell, Wahlgren, & Gehrman, 2002) that situates the individual and family within a community, society and cultural context that heavily influences their life experiences and opportunities.

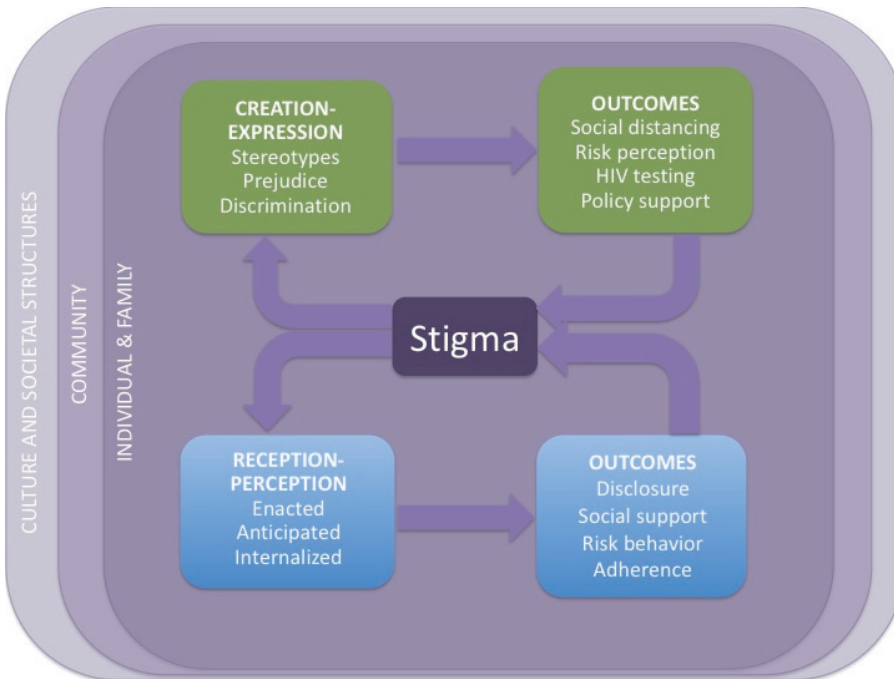


Figure 6: Conceptual Framework, Modified HIV Stigma Framework

A characteristic of the HSF which I did not modify but which could be examined in further research relates to the directionality of the arrows within the framework. The research in this thesis did not test the direction of the relationships, however in, for example, article III, we theorized that those women who received more family support appeared to suffer from less HIV-related stigma. In the original HSF, stigma should lead to the outcome of (more or less) social support, which does seem likely. However, it appears that the relationship could be bi-directional, with social support received, in turn, influencing the extent to which the stigma perceived is internalized. The same could be true of HIV testing, that instead of acting as an outcome, persons who have tested for HIV receive information that, in turn, reduces the stereotypes they hold or the stigma that they express. It might be of interest to depict the relationships between mechanism and outcome as bi-directional, however, the cycle also continues and perhaps this can denote that an outcome can be influenced by a mechanism and, in turn, act to influence the mechanism again in a cyclical process.

More in-depth qualitative work combined with prospective quantitative studies, or quantitative studies using structural equation modelling, could better examine these issues and further refine the framework.

Towards an emancipatory approach to stigma reduction

We have examined a number of ways that stigma serves as a barrier to HIV prevention and care in the Vietnamese context. As I have tried to show in this thesis, many of these influences are tied to cultural structures and influences, which strongly affect the way that individuals and families express and receive stigma, and enact HIV preventative and care-seeking behaviors.

There is increasing effort to reduce HIV-related stigma through individual, healthcare-focused or multi-component interventions in many settings spanning the globe (Gaudine, Gien, Thuan, & Dung do, 2009; Nyblade, 2008; Sengupta, Banks, Jonas, Miles, & Smith, 2010). Interestingly, in a systematic review of 19 interventions to reduce HIV-related stigma, only 2 were found to be both effective and to have been designed and evaluated rigorously (Sengupta et al., 2010). This was deemed partly due to a lack of studies, overall, targeting HIV-related stigma, despite it being identified nearly three decades ago as a significant problem and barrier to HIV prevention. It was also described that is difficult to obtain statistically significant measures, particularly measures of sustained change over time, through individual-level interventions, such as those described in the review.

Still, sustained efforts for the reduction of HIV-related stigma are needed if significant progress is to be made in the wider arena of HIV prevention and care and the question is how these might be achieved. In the beginning of this thesis I described the naturalistic and positivistic influences on much of biomedical and public health research traditions, including the approach used in this thesis. If I were to repeat this process, or to start a new project in which another approach could be taken, I would most likely advocate an emancipatory approach. Emancipatory approaches include a range of approaches, their common characteristic being a critique of the way that both positivistic and naturalistic approaches commonly involve powerful experts (scientists) engaged in research on individuals or communities who are, in comparison, powerless (Robson, 2002). They often analyze the experience of diverse and powerless individuals in society and try to understand why societal power dynamics are unequal. These approaches are often closely tied to social and political action (Robson, 2002).

An emancipatory approach would engage community members and address the structural and cultural issues identified in this thesis in Vietnam and elsewhere as strongly influencing HIV-related stigma towards persons living with HIV (Castro & Farmer, 2005; Parker & Aggleton, 2003). Some examples of this have been tried on small scales in Vietnam, where participatory action research approaches have involved community members and conducted community-led multi-component interventions to reduce HIV-related stigma (Gaudine et al., 2009; L. Nyblade et al., 2008). What is needed is for these to be scaled-up to much larger levels, where long-standing and widespread societal impact might be made.

CONCLUSIONS

This thesis aimed to analyze and explore how HIV-related stigma influences HIV prevention and care in a concentrated HIV epidemic context. The thesis analyzed Vietnamese adults' views towards persons living with HIV and behaviours in relation to HIV testing. In addition, coping with HIV was explored among women living with HIV. Finally, barriers to adherence were explored among people taking antiretroviral therapy and their family members.

The results suggest that stigma is created and received by both HIV-positive and HIV-negative individuals and that stigma presents an obstacle to effective HIV prevention and treatment in the Vietnamese context. The main conclusions to be drawn from this thesis include the following:

- Women, persons with less education, and those who had not migrated out of the rural area were more likely to express stigmatizing attitudes toward people living with HIV. (I)
- HIV-related stigma was associated with not feeling at-risk for HIV among rural Vietnamese adults. (I)
- Testing rates for HIV were low, generally, and persons with less money, those living in more rural settings, and those expressing more HIV-related stigma were less likely to have tested for HIV. (II)
- Prevention of mother-to-child transmission programs seemed not to have had a large uptake in the study population, with pregnant women no more likely to have tested for HIV than non-pregnant women. (II)
- Stigma appeared to affect the extent to which persons living with HIV could enact HIV prevention measures or disclose their HIV status to others. (III, IV)
- Women living with HIV attempted to stave off HIV-related stigma by enacting culturally-prescribed feminine virtues of protecting others and appearing innocent in their infection with HIV. (III)
- Family was identified as an important source of adherence and social support and those women who had more support from family members appeared to cope more easily with the stigma of living with HIV. (III, IV)
- Organizations for persons living with HIV helped people living with HIV to obtain health care and to manage stigma. (III)
- Stigma was identified as one of the main barriers to adherence to ART, causing people living with HIV to hide or delay taking their medication. (IV)

POLICY AND RESEARCH IMPLICATIONS

Successful HIV prevention is highly dependent on targeted messages that are understood, absorbed and enacted by the population and on adherence to prevention measures such as condom use, needle and syringe programs, opioid substitution therapy or prevention of mother-to-child transmission. Successful treatment of HIV is dependent on the early detection of the virus through testing and the uptake and adherence to ART. Overall, effective HIV prevention and treatment are both heavily dependent on the extent to which stigma serves as a barrier to receiving and enacting prevention and treatment strategies. Some of the findings from this thesis point to areas in policy and research where immediate action can be taken to enhance prevention and care efforts in the Vietnamese context:

The provision of free, opt-out, high-quality HIV testing could help to normalize the process of HIV testing and make it more accessible within Vietnam, particularly in the antenatal setting.

Family and peer support, combined with strategic planning for how to adhere to medication regimes, could help support good adherence.

Organizations for persons living with HIV can be used to increase access to health care, to reduce stigma in community and family settings, and increase quality of life for persons living with HIV.

Elements of the cultural notion of protection could be harnessed for HIV prevention and adherence. Targeting messages to women, and possibly to men, to emphasize safe sex, safe injecting, and HIV testing or adherence to treatment to “think of your family” would support the cultural value of interdependency and responsibility for others within the family.

Refined public health messaging is needed in relation to HIV risk in Vietnam. Past injecting drug use should be more clearly linked to HIV infection risk and persons with a history of injecting drug use should be targeted for HIV testing. HIV testing should be encouraged prior to marriage or new sexual relationships. Finally, all HIV prevention messages must be de-linked from fear-based messaging and the language of “social evils”.

Latent class analysis and targeting of undecided or “ambivalent” individuals could provide an opportunity for stigma reduction if targeted through an audience segmentation approach with a highly effective intervention.

The HIV Stigma Framework should continue to be tested conceptually, particularly with a closer focus on men living with HIV, in the Vietnamese context to help understand the processes of HIV-related stigma and to identify points for intervention.

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APPENDICES

APPENDIX I: QUESTIONNAIRE USED IN STUDY A (ARTICLES I & II)



Study on perceptions/knowledge about HIV of people in Bavi District

Dear sir/madam, this is a study on perceptions and knowledge about HIV of people in Bavi district. If you participate, your answers will only be used for research purposes, encoded and kept confidential. If at any point during the interview you do not feel comfortable with any of the questions, you can refuse to answer and/or ask to stop the interview.

1. Agrees to participate

2. Does not agree to participate

1. Household leader's name: Household nr:

2. Individual name: Individual nr:

3. Sex: ☐ 1. Male ☐ 2. Female

4. Date: ____/____/2007

Age:

5. Place of interview: 1. Household 2. Other (*specify*):

Interviewer name: Signature:

Supervisor name: Signature:

1 Have you heard of something called HIV/AIDS?

☐ 1. Yes ☐ 2. No-> **stop interview**

☐ 88. No answer

2 Where have you heard about HIV or AIDS?

Do not prompt, ask "anywhere else?" (can have one or more responses)

☐ 1. Radio

☐ 5. Posters

☐ 2. Television

☐ 6. Friends/relatives

☐ 3. Magazine/newspapers

☐ 7. Health worker

☐ 4. Propaganda team/Women's union

☐ 88. No answer

☐ 8. Other source _____

3 If you had a question or needed more information about HIV or AIDS, who would you ask? *Do not prompt, ask "anywhere else?" (can have one or more responses)*

☐ 1. Village leader

☐ 3. Friends

☐ 2. Health worker

☐ 4. Relatives in family

☐ 5. Don't know

☐ 88. No answer

☐ 6. Other _____

- 4 How can people protect themselves from becoming infected with HIV, the virus that causes AIDS?

Do not prompt, ask "any other way?" (can have one or more responses)

- ☐ 1. Using condoms when having sex
☐ 2. Do not have sex
☐ 3. Faithful in one wife and one husband
☐ 4. Do not have sex with prostitute/many partners
☐ 5. Using clean needles/ not sharing
☐ 6. Not drug uses
☐ 7. Preventing transmission from mother to child
☐ 8. Preventing social evils and bad behavior
☐ 9. Other : _____
☐ 10. Don't know
☐ 88.No answer

- 5 Do you think that a healthy-looking person can transmit HIV, the virus that causes AIDS?

- ☐ 1. Yes
☐ 2. No
☐ 3. Not sure/maybe
☐ 88. No answer

- 6 Do you know which ways of spread HIV ? (Don't suggest, ask "in which ways" can be one or more than one answers)

- ☐ 1. Transmit from mother to child ☐ 5. Mosquito bite
☐ 2. Blood transfusion ☐ 6. Sharing meal
☐ 3. Sharing needles ☐ 7. Kissing, shaking hands, hug
☐ 4. Having sex ☐ 8. Don't know
☐ 9. Other: _____
☐ 88. No answer

- 7 Do you think that you are personally at risk for getting HIV, the virus that causes AIDS?

- ☐ 1. Yes ☐ 3. not sure/maybe
☐ 2. No -> **Go to Q. 9** ☐ 88. No answer

- 8 If yes (to Q. 7), why do you think you might be at risk for HIV?

- 9 According to you, can HIV be passed from a mother to her baby during pregnancy and/or delivery?

- ☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer

10 According to you, are there any ways to know whether someone gets HIV/AIDS?

- ☐ 1. Yes ☐ 3. Maybe
☐ 2. No -> **Go to Q. 15** ☐ 88. No answer

11 I do not want to know the results, but have you ever been tested to see whether you have HIV?

- ☐ 1. Yes ☐ 3. Not sure
☐ 2. Not yet ☐ 88. No answer

12 Do you want to have a HIV test this year?

- ☐ 1. Yes ☐ 3. Maybe
☐ 2. No -> **Go to Q. 15** ☐ 88. No answer

13 If you wanted to be tested for HIV/AIDS, where would you go for testing? (*can have one or more responses*)

- ☐ 1. Heath station (commune) ☐ 4. Central hospital
☐ 2. General hospital/ District hospital ☐ 5. Private health center/private doctor
☐ 3. Provincial hospital ☐ 6. Don't know
☐ 88. No answer
☐ 7. Other _____

14 Continues from Question 13
 Why do you choose the above health service?
 (*May have one or more than one answers*)

- ☐ 1. Privacy ☐ 5. Cheap/ Free of charge
☐ 2. Convenient ☐ 6. Good furniture
☐ 3. High qualification ☐ 7. Serving as demand
☐ 4. Friendly staff ☐ 8. Friend's recommendation
☐ 88. No answer ☐ 9. Other _____

15 Do you know anyone who is infected with HIV or who has died of AIDS?

- ☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer

16 In your community, in what ways do people know if someone has HIV? *Do not prompt, ask "Any other ways"? (Can have more than one answer)*

- ☐ 1. Person with HIV discloses
☐ 2. Partner/husband/child was ill or died
☐ 3. Rumor
☐ 4. That person looks ill and loses a lots weight
☐ 5. Drug users, prostitutes, many partners
☐ 6. Friends/ neighbor of HIV + person will tell
☐ 7. From health workers/ health center
☐ 8. HIV + person's family tell
☐ 9. Don't know
☐ 10. Other: _____

- 17 Are there persons in your community who you think sometimes use needles to inject drugs such as heroin?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 18 Are there persons in your community who you think sell or buy sex (prostitutes or the clients of prostitutes)?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 19 According to you, do you think that you like everybody have enough information to prevent HIV/AIDS?
☐ 1. Yes/Enough ☐ 3. Don't know
☐ 2. Not enough, want to know more ☐ 88. No answer
- 20 According to you, should people with HIV/AIDS be ashamed?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 21 According to you, is it safe for children to play with people with HIV/AIDS?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 22 According to you, should people with HIV/AIDS be isolated??
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 23 According to you, will promiscuous women spread HIV/AIDS in community?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 24 According to you, do education training centers for drug users and prostitutes help to stop transmission of HIV/AIDS in the community?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 25 According to you, would you like to be friends with someone who has HIV/AIDS?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 26 Would you be willing to share a meal with a person who has HIV/AIDS??
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 27 Do you think that people with HIV/AIDS are promiscuous people?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 28 According to you, will a promiscuous man transmit HIV/AIDS in the community?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 29 If a student has HIV but is not sick, should he or she be allowed to continue in school with other students?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 30 Would you be ashamed if someone in your family had HIV/AIDS?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
☐ 4. Depends on the circumstances (cause of infection)

- 31 Do you think that HIV is a big problem in your community?
☐ 1. Yes ☐ 3. Not sure/maybe
☐ 2. No ☐ 88. No answer
- 32 How often do you go away from your home?
☐ 1. Daily ☐ 4. 3-6 times/year
☐ 2. Weekly ☐ 5. One-two times/year
☐ 3. Monthly ☐ 6. Never -> **End interview**
- 33 Reasons for going away from home (*can have one or more answers*)
☐ 1. Go to work ☐ 3. Travel
☐ 2. Visit friends/ relatives ☐ 4. Other (*comment*):

- 34 Where did you go? (*can have one or more answers*)
☐ 1. Hanoi
☐ 2. Within Bavi district
☐ 3. Within Hatay province
☐ 4. Other province: _____

Thank you very much ☐

APPENDIX II: INTERVIEW GUIDE FOR ARTICLE III

Understanding the experience of people living with HIV in the Hanoi area: Stigma, discrimination and access to health care services

Start tape recorder! Explain purpose of the interview and obtain consent: We wish to talk to some people who are HIV+ in the community to learn more about their views and how health workers can support them. If you choose to take part in this interview you can refuse to answer any question or ask us to stop at any time with no penalty. Also, we will not use your name or any identifying information about you when we write down or use this information that you are telling to us today. Is it okay for you to participate in the interview? Is it okay for us to tape-record the interview?

“Breaking the ice”: Chatting about- if they live in this commune, etc.

What is your life like now?

Probe: What do you do for a living? Who do you live with? Who is in your family? What activities do you most enjoy? What is the hardest thing in your life right now?

Can you tell me the story of how you came know your status of being HIV positive?

Probe: When did you find out? Why were you tested? How do you suspect you became infected? What did you feel when you found out your status?

What is your life like now?

Probe: How do you feel about your HIV status? Do you ever feel very sad? How is your health currently? Are you on treatment? Are you working? Who have you told about your HIV status?

Do you receive health care for your HIV?

Probe: If so, where? Why do you go there? How are you treated there? Can you describe any barriers you feel for you in getting the health care you need?

Do you feel you have received information about how to prevent the spread of HIV?

Probe: From whom? Is it more after you were diagnosed with HIV? What has been most helpful information for you? What can you do to prevent the spread of HIV?

Have you experienced discrimination since your HIV diagnosis?

Probe: In what way? From who? Where do you feel that discrimination is the worst? Sharing meals?

Have you experienced feeling ashamed or labelled based on your HIV status?

Probe: In what way? From who? Where do you feel you are most ashamed? Least ashamed? Do you feel worried that people connect HIV with bad behavior (drugs, etc)?

What are your biggest struggles in living with HIV?

Probe: how are your relationships with family? With in-laws family (if appropriate)? With friends? With community leaders? With healthcare staff? How is the family financial situation? Your job situation? What could make these struggles more manageable for you?

APPENDIX III: FOCUS GROUP DISCUSSION GUIDELINE ARTICLE IV

1. What are the main obstacles for you to take ART as prescribed?

a. Is it difficult to take drugs on time? If so, why?

2. Do you have any special strategies to take ART as prescribed?

If so what are some of those strategies?

3. Do you have someone supporting you with your ARV medication?

If so, who and in what way do they support you?

4. What support would be best for you to take your medications regularly?

Explore different ideas, advantages – disadvantages

How could the health system contribute?

5. Would it be an advantage to have someone coming to your house with ART on regular basis?

If so, explore how often, etc.

6. If there were distribution of ART in the community, who would be most suitable to distribute them?

Probe specifically regarding health workers, volunteers, PLHIV

7. What obstacles / problems do you see with distributing ART in the community?

Open discussion, explore effects of stigma and discrimination if not brought up spontaneously

APPENDIX IV: THEME, CATEGORIES AND CODES FROM ARTICLE IV

Theme	PLHIV's views on ART adherence and optimal care delivery are influenced by their experiences of HIV-related stigma				
Categories	<i>Stigma-related barriers to ART adherence</i>	<i>Strategies for ART adherence</i>	<i>PLHIV's needs for support in adhering to ART</i>	<i>PLHIV do not want home-based directly observed therapy</i>	<i>PLHIV can provide support to other PLHIV</i>
Codes	<p>Fear of unwanted disclosure</p> <p>Fear others will suspect them of taking illicit drugs</p> <p>Interruption when medication should be taken</p> <p>Lack information about ART side effects</p> <p>Work faraway/ travelling from home</p> <p>Hard to talk frankly with others</p>	<p>Conceal</p> <p>Construct alternate stories</p> <p>Postpone and take dose later</p> <p>Form a new habit (ie, alarm, schedule)</p> <p>Call health staff when unsure</p> <p>Carry drugs with you when away from home</p> <p>Have someone remind you</p>	<p>Moral support</p> <p>Good rapport with health staff</p> <p>More information and counselling</p> <p>More information and counselling for relatives</p> <p>Reminders about taking ART</p> <p>Help talking to relatives</p>	<p>Could incite stigma</p> <p>Tied to home while waiting for drug delivery</p> <p>Go to clinic to be sure about health status</p>	<p>Similar experiences</p> <p>Easy to talk to</p> <p>Show sympathies & concern</p> <p>They can advocate for us</p> <p>Need to be trained</p> <p>Should not be active drug users</p> <p>Should be peer-selected</p> <p>Can share strategies</p>

